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ABSTRACT

The report describes activities and findings of an 18-month project which surveyed day and other non-residential services provided to persons with mental retardation in the Commonwealth of Massachusetts. An introductory section describes project purposes, followed by a description of project methods (sampling plan, questionnaire development, conduct of interviews, and data processing and analysis). Results of the quantitative analyses are presented, categorized according to interview responses given by service consumers, family members, agency board and parent group members, administrative staff, and community area mental retardation coordinators. Results are then interpreted, focusing on the areas of service planning and delivery, community involvement, and administrative support. Thirteen policy and practice recommendations are presented in three major areas: availability of services, overall system flexibility, and direct care program staff. Recommendations include developing integrated vocational models, using existing resources for transportation and recreation services, identifying systemic barriers to program innovation, and improving the salaries of direct care staff. (JW)

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THE STATUS OF DAY AND OTHER NON-RESIDENTIAL SERVICES IN MASSACHUSETTS: ENHANCING PROGRAM CAPABILITIES

FINAL REPORT

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THE STATUS OF DAY AND OTHER NON-RESIDENTIAL SERVICES IN MASSACHUSETTS: ENHANCING PROGRAM CAPABILITIES

FINAL REPORT

Prepared for: The Mental Retardation Committee of the Governor's State Advisory Council on Mental Health and Mental Retardation

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November 1, 1986

The Mental Retardation Committee

of The Governor's State Advisory Council

on Mental Health and Mental Retardation

Presents

ENHANCING PROGRAM CAPABILITIES:

THE STATUS OF DAY AND OTHER NON-RESIDENTIAL SERVICES IN MASSACHUSETTS

This project was supported by the Massachusetts Department of Mental Health. The views expressed herein are soley those of the authors and members of the Mental Retardation Committee of the Governor's State Advisory Council on Mental Health and Mental Retardation. As such, these views should not be construed as representing the opinions or policy of the Massachusetts Department of Mental Health or any other state agency.

THE STATUS OF DAY AND OTHER NON-RESIDENTIAL SERVICES IN MASSACHUSETTS: ENHANCING PROGRAM CAPABILITIES

FINAL REPORT

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NOVEMBER 1, 1986

PREFACE

Prior to the 1970's, persons with mental retardation in Massachusetts were served primarily in institutions. With Consent Decrees and growing public awareness came the recognition of the need for an array of services across the Commonwealth.

During the 1970's a state level Citizens' Advisory Council was established along with citizen area boards to assist in the development of a comprehensive state service system. Through this process the Mental Retardation Committee was established to advise the Department of Mental Health on issues effecting the population served by the Division of Mental Retardation. The Committee's mandate is to advocate for the development of a system of services that will meet all the neeeds of this population. The Committee, with other citizen groups and organizations, advocates for the much needed additional funding and changes that now support and finance this system.

In the 1980's, advocacy is focused on the service needs of each individual. Today, thousands of citizens with mental retardation are served in a multitude of settings as we continue to work toward a system of superior services.

This project examines a major area that needs greater emphasis, that of the day and other non-residential services. The results of this survey demonstrate where there is room for improvement. We have recommended what must be altered, to increase our present system's capabilities and effectiveness.

ACKNOWLEDGEMENTS

The coordinated efforts of many dedicated people have made this report possible. Their singular motive is that the publication of this information lead to necessary improvements in the services provided to persons dependent on the Division of Mental Retardation.

We would like to express our appreciation to all the members of The Mental Retardation Committee. These citizen advocates spent many months in the planning, development and implementation of this report.

We particularly wish to thank the many citizens who volunteered to assist the Committee in conducting the interviews throughout the Commonwealth.

We gratefully acknowledge the active support of Ned Murphy, Commissioner of the Department of Mental Health, Mary McCarthy, the Deputy Commissioner for the Division of Mental Retardation, and George Zitney, former Assistant Commissioner of the Division of Mental Retardation.

Major credit for the success of this report must go to the Division staff members. Susan Mullen worked with the Committee to develop the initial survey design and functioned as the project coordinator. Mark Ostrowsky provided the Committee withhis expertise on the Division's Day Services Programs. Deborah Brunet-Tuttle, student intern, coordinated the volunteers and site visits and was responsible for maintaining project data.

Many thanks to our consultants. John Hornik, Department of Mental Health Research Director, and Marsha Seltzer, Assistant Professor at the Boston University School of Social Work gave early assistance to the Committee in the development of the project design. John Agosta and Anne Howard helped train volunteers, analyzed the data and prepared the report for Committee approval.

We especially wish to bring to your attention the true heroes of this report - the people within the areas surveyed, who agreed to be interviewed. Their candid responses produced the data base for the Mental Retardation Committee's recommendations.

DEDICATION

" IN MEMORIAM "

When a dear friend departs the cherished memories remain.
Our friend, Shirley Sheingold has passed away.

We knew her well by reason of her many years of dedicated services to persons with mental retardation.

Her contributions to the Mental Retardation Committee of the State Advisory Council reflected the influence of her thorough understanding for the needs of persons with mental retardation.

To this Committee and to her many friends, her life stands as a challenge to those who follow. To those of us who know her as a friend she leaves a void and a great emptiness which cannot be filled except in part from the memories of our association with her, her friendly hospitality, the warm smile are the things we remember of our friend Shirley Sheingold.

TABLE OF CONTENTS

TOPIC PAGE

PREFACE i

ACKNOWLEDGEMENTS ii

DEDICATION iv

TABLE OF CONTENTS v

I. INTRODUCTION AND PROJECT PURPOSES 1

A. Structure and Role of the Mental Retardation Committee 1

B. The Day Services Project 1

1. Background of the Project 1
2. Purpose of the Project 2
3. Overview of the Project 2

II. PROJECT METHODS 3

A. Project Sampling Plan 4

1. Area Selection 4
2. Program Selection 6

B. Development of the Questionnaire 8

1. Persons Interviewed 8
2. Areas of Inquiry 12

C. The Interviewers 13

D. The Conduct of the Interviews 14

1. General Format 14
2. Selection of Respondents 15
3. Number of Respondents by Source of Information 16

E. Data Processing and Analysis 17

1. Qualitative Questions 17
2. Quantitative Questions 17
3. Data Compilation and Analysis 17

III. RESULTS OF THE QUANTITATIVE ANALYSES 19

A. Service Consumers 19

B. Family Members 23

C. Agency Board and Parent Group Members 26

D. Administrative Staff 29

E. Community Area Mental Retardation Coordinators 33

F. Comparison of Selected Responses 35

IV. INTERPRETATION OF RESULTS 46

A. Conceptual Framework Used to Guide Interpretation 46

B. Service Planning and Delivery 51

1. Satisfaction with Individual Service Plans 51
2. Program/Service Availability 52
3. Program/Service Accessibility 53
4. Program/Service Content 56

C. Community Involvement 56

1. Involvement of Board Members 56
2. Community Participation 57
3. Use of Existing Community Resources 58
4. Involvement of Private Sector Businesses 58

D. Administrative Support 59

1. Management Practices 59
2. Adequacy of Funding 60
3. Service Delivery Staff 61
4. Quality Assurance 62
5. Flexibility 65

V. POLICY AND PRACTICE: RECOMMENDATIONS AND FUTURE INQUIRY 66

A. The Availability of Services 67

1. Consider the Preferences of Consumers 68
2. Encourage Family Involvement 69
3. Develop Integrated Vocational Models 69
4. Consider the Need for Segregated Vocational Models 70
5. Develop Policy and Incentives to Develop Family Supports ... 70
6. Use Existing Resources for Trans. and Recreation Services .. 71
7. Assess the Value of the Present Quality Assurance System ... 71
8. Examine Policy Regarding Frequently Unserved Populations ... 72

B. Overall System Flexibility 73

9. Identify Systemic Barriers to Program Innovation 73
10. Encourage Needed Program Innovation and Reform 74

C. Direct Care Program Staff 74

11. Improve the Salaries of Direct Care Staff 75
12. Examine Existing Labor Markets 76
13. Make Greater Use of Community Colleges 77

D. Conclusion 78

I. INTRODUCTION

A. Structure and Role of the Mental Retardation Committee

The Mental Retardation Committee (MR Committee) is a component of the Governor's Advisory Council on Mental Health and Mental Retardation (SAC), consisting of 14 members who reflect a balance in philosophy, ideology and geography. Also included are individuals who want to serve on the committee but who have a conflict of interest (i.e., they are associated with a vendor agency). These individuals are able to serve as consultants to the committee rather than regular members.

B. The Day Services Project

1. Background of the Project

The Division of Mental Retardation (DMR) within the Department of Mental Health is charged with establishing and maintaining a comprehensive, area-based system of training, support, placement, and follow-up services to persons with mental retardation. These services are delivered in community-based and institutional settings and are either purchased under contract from private agencies or are state-operated. Beginning in FY 1984, the Division of Mental Retardation addressed the priority of redirecting or expanding services to targeted special populations. In FY 1985 this focus included the provision of community-based services to individuals losing their entitlement to special education (Chapter 766) services at the age of 22 years. Additionally, in FY 1986 populations who have previously been unserved or underserved have been targeted.

These include adults with mental retardation living in the community, and consumers identified as elderly, autistic, and/or deaf-blind. This report is only one indication of the emerging focus in Massachusetts on existing day and other non-residential services.

2. Purpose of the Project

The Mental Retardation Committee, in cooperation with the Department of Mental Health, has identified the provision of day and other non-residential services for persons with mental retardation as a vitally important area of concern. For more than a year and a half, the Committee has focused on this area by conducting a survey of these services currently available for adults with mental retardation in the Commonwealth. Their project, detailed in this report, had three primary purposes:

- To offer members of the MR Committee an opportunity to become more familiar with the the day and other non-residential services and programs that are available for persons with mental retardation;
- To obtain information for the MR Committee that will enable its members to make informed recommendations regarding the the current and future delivery of services; and
- To answer the following question -- What needs to be done to improve day and other non-residential services for persons with mental retardation in the Commonwealth of Massachusetts?

It is important to note that members of the MR Committee are interested in more than simply identifying and describing services as they currently exist. The Committee seeks to facilitate consumer access to, and participation in, a wide range of social, recreational, and vocational opportunties.

3. Overview of the Project

This project was conceived, designed and completed as a "citizen participatory project." Although technical and other professional

support was provided by the Department of Mental Health, the project was directed by the MR Committee. During the 18 months this project spanned, members of the committee contributed substantially to each project activity, including the design of a sampling plan and the questionnaires, collecting information, analyzing the results, and preparing this final report.

To achieve this project's purposes, members of the MR Committee and other concerned citizens visited programs in 12 DMH Areas across the Commonwealth. They spoke at length with over 175 persons, including consumers, family members, program directors, area mental retardation coordinators, and persons serving on vendor agency governing boards. Of particular interest was the information these persons could provide regarding the status of and need for day services such as day habilitation centers, work activity centers, sheltered workshops and supported employment, and other non-residential services including transportation, recreation, respite care and in-home family supports.

II. PROJECT METHODS

A. Sampling Plan

1. Area Selection

The Massachusetts legislature divides the Commonwealth into seven districts and 40 areas for the organization of service delivery by the Department of Mental Health. Since the scope of this project did not allow for the study of all programs in all areas, a strategy was devised to select a representative sample of programs located in 12 areas. In selecting these 12 areas, care was taken to choose those that represent a broad range of socio-demographic characteristics. Four socio-demographic factors were used as criteria to select areas: (a) percentage rural population, (b) per capita income, (c) percentage minority population, and (d) per captia funding for mentgal retardation day services.

Census data from 1980 and DMH records were used as information sources. Based on these data, each area was assigned a score of high, medium, or low on each of the four socio-demographic factors. Figure 1 provides an explanation of the scoring criteria.

Figure 1: Scoring Criteria Along Four Factors

SOCIO-DEMOGRAPHIC CHARACTERISTIC	HIGH SCORE	MEDIUM SCORE	LOW SCORE
URBAN/RURAL (PERCENT RURAL POPUL)	0-20%	21-45%	46-70%
PER CAPITA INCOME	$5,000-$7,000	$7,001-8,500	$8,501-$10,500
MINORITY POPULATION (PERCENT NON-WHITE)	1-20%	21-45%	46-70%
MR FUNDING FOR DAY SERVICES* ($/PER CAPITA)	$2.00-$4.50	$4.51-$7.00	$7.01-$10.00

* Day Services include day, vocational and support services.

Given these criteria, a master chart was developed that allowed the Committee to consider the scores of each area on the four factors. The four factor scores were considered together rather than separately because of the interdependent nature of the factors (e.g., high percentages of minority populations frequently are found in areas with a low percentage of rural population). Areas selected do not necessarily represent typical areas in the state. Rather, given the socio-demographic characteristics considered, they are representative of the diversity among areas in the state. When a number of areas appeared to have similar profiles on the basis of these four factors, attention was paid to the distribution of study areas across the state and representative areas were chosen by random selection. Figure 2 lists the 12 areas selected and the scores for each area on the four socio-demographic factors.

Figure 2: Twelve Selected Areas and Their Scores on Four Socio-demographic Factors

AREA*	DISTRICT	PER CAPITA INCOME	MINORITY POPULATION	URBAN/RURAL	MR FUNDS
A	1	LOW	LOW	LOW	MEDIUM
B	1	MEDIUM	LOW	LOW	HIGH
C	2	LOW	LOW	HIGH	MEDIUM
D	3	MEDIUM	LOW	MEDIUM	MEDIUM
E	3	MEDIUM	LOW	LOW	LOW
F	4A	HIGH	LOW	MEDIUM	MEDIUM
G	4B	HIGH	LOW	LOW	LOW
H	5	LOW	LOW	MEDIUM	MEDIUM
I	5	MEDIUM	LOW	HIGH	LOW
J	6	MEDIUM	HIGH	LOW	MEDIUM
K	6	LOW	MEDIUM	LOW	MEDIUM
L	6	LOW	HIGH	LOW	MEDIUM

* Areas are not listed by name, given assurances regarding the confidentiality of the information collected. The alphabetical labels assigned to the areas are used throughout the text whenever a specific area is noted.

2. Program Selection

Once the 12 areas were selected, programs within each area had to be identified for study. Particular attention was paid to selecting those programs that provide unique services as well as those that address the needs of the overall population of persons with mental retardation and others with low incedence disabilities. It is notable that these program types extend beyond traditional day services to include community-based supportive services such as respite care and specialized home care.

The following definitions regarding the seven targeted program types were extracted from material published by the Department of Mental Health:

- Day Activity -- This service provides training in activities of daily living, social skills, and language development. If appropriate, training in prevocational skills may also be provided;

- Day Habilitation -- These programs provide short term, medically-oriented therapy and training through intensive intervention during the day. The goal of these programs is to stabilize the consumer and enable him/her to access a wider range of training opportunities;

- Work Activity -- These programs provide training in pre-vocational and/or vocational skills. The service is therapeutic in nature, and designed to address specific disabling conditions of consumers. The goal of work activity programs is to assist the consumer in developing the skills necessary for placement in a vocational program;

- Sheltered Workshop -- These programs provide assessments of the individual's strengths and weaknesses in work-related skills, and training in work and production skills. Sheltered work services may prepare the consumer for a less restrictive employment program or competitive employment;

- Transitional Employment -- (On-site Work Programs, Apprenticeship Programs) Transitional employment services provide work-related skills training and assistance to consumers in order to progress to competitive employment. Services may include job placement development, vocational training, on-site supervision, support and follow-up;

- Respite Care -- Respite care can be provided either in-home or out of home. In-home respite is short-term care, given by qualified care providers, which not only originates in the home of the consumer, but also supports the consumer's ability to continue to remain living at home. Out of home respite care places the consumer outside of his/her home on a short-term basis. Both types of respite care services are provided to relieve a crisis in the consumer's life or family, and to restore or maintain the physical and/or mental well-being of the consumer and family; and

- Specialized Home Care -- Two distinct types of specialized home care programs exist: in-home and out of home. In-home specialized home care services use trained staff to provide instruction in skill development and/or behavioral management to consumers and their families in the dwelling of the consumer's family. Out of home specialized home care is a service which provides consumers with a home and training via recruiting qualified care givers who offer the consumer room, board, and a home environment. In both types of specialized home care, the instructor or care giver has access to professional consultation from clinicians who are working with the consumer.

The committee acknowledges that there are substantial differences among programs that fall into the same category. For three of the categories described above -- transitional employment, respite care, and specialized home care -- the number of programs in the 12 Areas was small enough to allow the Committee to study all existing programs. For the other four program categories, specific programs were selected with respect to the following three factors: (a) size of vendor, (b) location in the community or within a state school or regional center, and (c) consumer population served by the program. The Committee sought to study programs administered by small as well as large vendors, programs provided in the community as well as those in the state schools and regional centers, and programs serving low incidence populations as well as those serving consumers with mild, moderate, and severe handicaps.

During the program selection process it was found that different program types were not consistently available within each area. For

example, while some areas have developed a range of on-site and transitional work programs, others have not. Although the Committee believes that it is important to acknoweledge these differences, no attempt is made to make comparisons among areas in the Commonwealth.

Using the criteria described, 77 programs from 12 areas were selected for the survey. Due to time limitations and finite volunteer resources, this number had to be decreased. Whenever possible, the original sampling framework was followed and attention given to studying a diversity of programs representing the seven program categories. However, because programs in state schools and regional centers were scheduled to be surveyed after the community surveys were completed, time limitations had a significant effect on the surveys planned for state school programs. To maintain some representation of programs in institutional settings, the decision was made to try to survey at least two day programs at each of the state schools (N=5) and regional centers (N=2). Only those institutional programs that were perceived by facility administrators as being representative of the range of programs offered in that facility were surveyed. In summary, Figure 3 displays information on the community areas and state schools that were included in the survey and lists the number of site visits each was accorded.

C. Development of the Questionnaire

Once programs had been selected, the MR Committee focused on selecting whom to interview and what questions to ask.

1. Persons Interviewed

To reach MR Committee's stated goal of obtaining a broad range of information on day and other non-residential services, numerous perspectives on a given program and the overall system of service

Figure 3: Areas Surveyed by Number of Visits

AREAS SURVEYED -- COMMUNITY BASED PROGRAMS

AREA	DISTRICT	NUMBER OF COMPLETED VISITS
A	1	6 completed site visits *
B	1	4 completed site visits *
C	2	3 completed site visits
D	3	6 completed site visits
E	3	4 completed site visits
F	4A	5 completed site visits *
G	4B	3 completed site visits
H	5	4 completed site visits
I	5	3 completed site visits
J	6	2 completed site visits
K	6	1 completed site visit
L	6	2 completed site visits
	TOTAL NUMBER:	40 site visits

* Material from one site visit in each of these areas was not returned for analysis

PROGRAMS SURVEYED -- STATE SCHOOLS/REGIONAL CENTERS

STATE SCHOOL/REGIONAL CENTER	NUMBER OF PROGRAMS VISITED
A	2 programs visited
B	2 programs visited
C	1 program visited
D	1 program visited
E	2 programs visited
F	2 programs visited
G	2 programs visited
TOTAL NUMBER:	12 completed packets

delivery was sought. As a result, Committee members decided to interview several people involved with each of the selected programs. Consumers and parents provided individual and personalized perspectives on their experiences. Community and state school administrative staff shared another perspective on the programs offered, while Area Mental Retardation Coordinators provided a

broader perspective on systems issues as well as on how specific programs fit into the service system. Additionally, Committee members interviewed citizen board and parent group members. By doing so, the Committee sought to facilitate increased cooperation and information flow from citizen boards across the state to the MR Committee. A high priority among MR Committee members is to learn more about the role that citizen boards and parent groups play in the development and delivery of day services for persons with mental retardation. A brief description of the types of persons surveyed is as follows:

- Consumers -- Individuals receiving services from the Department of Mental Health's Division of Mental Retardation and currently participating in a program being surveyed;
- Family Members -- Family members, usually a parent or sibling, of a consumer participating in a program being surveyed;
- Citizen Board/Parent Group Members -- All vendor agencies in the Commonwealth have citizen governing boards that are involved with agency operations and program development. Each state school and regional center has a parent group which functions in a similar capacity;
- Program Administrative Staff -- In community based programs, the Executive Director and/or the Program Director was interviewed. For state school and regional center programs, program directors were interviewed; and
- Area Mental Retardation Coordinators -- The Area Mental Retardation Coordinator was interviewed regarding community based services in the 12 areas surveyed.

Once a program had been selected, the Area Mental Retardation Coordinator was contacted. This person then arranged a site visit and interview schedule with individual program directors. Program directors then selected consumers, family members, and citizen board members to be interviewed.

For state schools and regional centers, superintendents were contacted first and each designated a contact person for the

project. This person was usually an administrator associated with day program operations within the facility. The contact person worked with the DMH Central Office representative to arrange for interviews.

Figure 4 contains summaries of the number of respondents, by category, interviewed in each area and state school or regional center included in the survey.

Figure 4: Survey Respondents by Type

COMMUNITY PROGRAMS

AREA	DISTRICT	CONSUMERS	FAMILY MEMBERS	BOARD MEMBERS	ADMINISTRATIVE DIRECTORS	MENT RET COORDINATORS
A	1	4	2	3	6	1
B	1	2	2	1	2	1
C	2	0	2	2	5	1
D	3	1	4	2	3	1
E	3	2	3	4	5	1
F	4A	3	4	3	4	2
G	4B	0	2	3	2	1
H	5	2	3	3	2	2
I	5	3	2	1	4	0
J	6	0	0	0	1	0
K	6	2	3	1	3	1
L	6	2	0	1	4	0
UNKNOWN	—	3	3	3	5	0
	TOTAL	24	30	27	46	11

INSTITUTION PROGRAMS

FACILITY	CONSUMERS	FAMILY MEMBERS	BOARD MEMBERS	ADMINISTRATIVE STAFF
A	2	2	1	2
B	1	1	0	2
C	1	0	0	1
D	1	1	0	2
E	2	2	0	2
F	1	1	0	1
G	1	1	2	2
TOTAL	9	8	3	12

2. Areas of Inquiry by Information Source

A questionnaire was developed for each of the five types of survey respondents. The questionnaires were of varying length and were modified appropriately for respondents associated with state schools and regional centers. Figure 5 contains a summary of the information domains contained in the five survey forms.

Figure 5: Information Sources by Respondent Type

INFORMATION DOMAIN	CONSUMERS	FAMILY MEMBERS	BRD MEM/ PAR GRPS	ADMIN STAFF	AREA MR COOR
1 ACTIVITIES UNDERTAKEN IN PRESENT PROGRAM	●				
2 EXPERIENCES WITH PRESENT PROGRAM	●	●			
3 ACTIVITY PREFERENCES OF CONSUMERS	●				
4 SOCIAL AND RECREATIONAL OPPORTUNITIES	●	●			
5 INDIVIDUAL SERVICE PLAN PROCESS AND OUTCOMES		●		●	●
6 ROLE OF CITIZEN BOARDS OR PARENT GROUPS			●	●	●
7 PRODUCTIVITY OF BOARDS OR PARENT GROUP MEETINGS			●		
8 PROGRAM NEED AND AVAILABILITY				●	●
9 QUALITY OF LIFE OF CONSUMERS		●		●	●
10 PROGRAM LICENSING AND MONITORING				●	●
11 ASSURING QUALITY WITHIN PROGRAMS				●	●
12 VARIOUS ADMINISTRATIVE AND STAFFING ISSUES				●	●

C. The Interviewers -- Recruitment, Training, Supervision

A group of forty-one (41) volunteers was recruited to conduct the interviews for the Day Services Project. Volunteers included parents and family members of persons with mental retardation, advocates, students from local colleges, members of the MR Committee and other interested members of the community. These citizen volunteers, many of whom were recommended by members of the MR Committee and other interested members of the community were contacted initially in April of 1985 by a DMH Central Office staff member who served as "Volunteer Coordinator." Volunteers who agreed to participate in the project were asked to attend one of two training sessions conducted by consultants to the project and staff from the Department of Mental Health. These training sessions were designed to increase the volunteers' understanding of the goals and logistics of the Day Services Project, to provide them with an understanding of the various types of programs and services included in the project, to acquaint them with fundamental interviewing skills, and to introduce them to the survey forms used in the project. Additionally, these training sessions gave volunteers the opportunity to meet others participating in the project from their geographic areas, and to meet the staff people that they would be in contact with throughout the interview phase of the project.

Site visits were conducted by teams consisting of two volunteers. To reduce the possibility of bias and facilitate objectivity, volunteers did not survey areas or programs from their own community, nor did they survey programs providing day or other services to a friend or relative. All site visits were coordinated and scheduled through a staff person at DMH central office. At least

two DMH central office staff members were identified as contact persons for any volunteer experiencing problems or having questions. As interviews were completed, survey forms were returned to the DMH Central Office where they were checked for completeness. The first interviews were conducted in July 1985 and the last in June 1986.

D. Conduct of the Interviews

1. General Format

As noted previously, site visits to the programs were made by teams of two volunteers. Teams were identified based on volunteer interests and geographic proximity. Prior to the site visits, survey packets were sent out to the areas and the program sites. These packets contained information pertaining to the purpose of the project and a full set of the five survey forms that would be used during the site visit. This was done to facilitate the collection of specific and extensive information during the actual interviews. Additionally, at the state schools and regional centers, staff were asked to review the survey form with the consumer(s) who would be involved in the interview process.

The teams chose to work in the manner in which they were most comfortable. In some cases the team members worked individually once they arrived on site, each conducting separate interviews with participating respondents. In other cases one volunteer would conduct the interview while the other was primarily responsible for recording information. Nearly all interviews were done in person and on-site.

As noted earlier, the survey forms were of varying length. Some were quite long and several contained a substantial number of open-ended questions. This type of question allows the respondent to

structure their answer to a question in any way they choose. Answers may be as short as one word, or they may be very long and detailed. While the answers to open-ended questions can provide a wealth of rich and informative material, the use of this type of question can result in some very lengthy interview sessions. Given the nature of this project and its goals, volunteers were instructed to focus on the questions of most interest to them, if time was limited and it appeared that not all the questions could be asked. This condition is extremely important to remember when interpreting the survey results. For some questions, the number of responses obtained is much smaller than for other questions on the same survey form. If no response was indicated on paticular form, it does not necessarily mean that respondents had no interest in the issue specified by the question. Rather, that particular question may have been omitted by the interviewer due to time restrictions.

2. Selection of Respondents

Critical to any survey is its sampling plan. Ideally, the persons responding to a survey will, when considered together, be representative of the entire population. In this survey a "purposive" sampling approach was used. This method is characterized by the use of judgement and a deliberate effort to select sample members that are representative of the population. In this survey, there were five target populations, each involved in some manner with a day or other non-residential program for persons with mental retardation.

To select respondents involved with community programs, project staff relied heavily on area mental retardation coordinators. Once contacted, this person arranged a site visit and interview schedule

with individual program directors. At the state schools and regional centers, site visits were arranged through the contact person identified by the Superintendent. In each case, appropriate administrative staff then selected consumers, family members, and citizen board members or parent group members to be interviewed. No attempt was made to randomly select respondents in any category. As a result, the MR Committee understands that there may be some bias inherent in the persons selected to serve as respondents.

3. Number of Respondents by Source of Information

As shown by Figure 6, during their site visits to community based programs, interviewers collected information from 24 consumers, 30 family members, 27 board members, 46 executive directors, and 11 mental retardation area directors. For the state school and regional center programs, 9 consumers, 8 family members, 3 board members, and 12 program directors were interviewed.

Figure 6: Respondents by Source

Respondent Categories	Community Programs	Institution Programs
Consumers	24	9
Family members	30	8
Citizen Board/Parent Group Members	27	3
Program Administrative Staff	46	12
MR Area Directors	11	--
TOTAL	138	39

It is important to understand why the same number of people in each category were not interviewed for either the community based programs or those in state schools and regional centers. Interview teams were usually able to visit a program site once only. If a consumer, family member, citizen board/parent group member was not available, it was difficult or impossible to conduct the interview another time.

E. Data Processing and Analysis

1. Qualitative Question (Open-Ended)

Open-ended questions are those in which the respondent is asked to provide his or her own answer to a question rather than selecting an answer from a list provided by the interviewer. Since the survey process used for this project consisted of face-to-face interviews, the interviewer was instructed to write down the respondent's answer exactly as stated. Some of the survey forms contained many open-ended questions while others contained relatively few questions of this type. As a result, some respondents responded to more open ended questions than others. For example, program directors were asked to answer 13 open-ended questions while citizen board/parent group members were asked only six open-ended questions.

2. Quantitative Questions (Closed-Ended)

Close-ended questions are those where the respondent must choose an answer from a set of pre-determined responses. In some cases the responses provided are categorical in nature, bearing no relation to one another. The respondent simply chooses the answer that best provides the information sought. In other cases, the responses provided reflect a pre-set hierarchy, calling for the respondent to make a judgement regarding the strength of his/her opinion on some topic (e.g., high to low satisfaction) or the status of some condition (e.g., very adequate to inadequate).

3. Data Compilation and Analysis

As interviews were completed and the survey packets were returned to DMH central office, answers to each question were analyzed. Responses given by persons associated with a community-based program were analyzed separately from those given by persons associated with

a state school or regional center.

Content analysis techniques were used as the primary means of analyzing responses to open-ended questions. That is, responses to each question were sorted by various divisions of interest (e.g., positive/negative response, responses of similar content). Given this tactic, simple trends in how people responded to questions were identified.

To analyze responses to closed-ended questions, the information provided on the survey forms was coded, placed onto computer disk and examined systematically using a computer-based analysis system (i.e., Statistical Package for the Social Sciences -- SPSS). The analysis was completed in three steps. First, responses to each closed-ended question were tabulated to reveal the number of times each pre-set response was chosen by respondents. Second, these tabulations were placed in table form, easing review of the information collected and allowing some comparison between responses offered by the various types of persons surveyed. Third, responses to certain questions were mathematically manipulated to compute "summed scores" (e.g., overall satisfaction with the ISP process) and other numeric indices (e.g., staff turnover rates). Overall, however, quantitative analysis were kept simple (e.g., frequency tabulations), given the intent of the study and the limitations of the data set.

III. RESULTS OF QUANTITATIVE ANALYSIS

As noted in Section II, five types of persons were interviewed: 1) consumers, 2) family members, 3) members of citizen boards of directors or state school parent groups, 4) administrative staff of community agencies or state schools, and 5) area mental retardation coordinators. The findings generated by these interviews are presented below by source of information, allowing a Question-by-question review of aggregated responses. A final additional section includes responses to question sets that were asked of more than one type of respondent and is presented in ways to encourage comparison between respondent types.

When reviewing these findings the use of a "purposive" sampling plan and the relatively small number of respondents should be kept in mind, especially with regard to the state schools. Consequently, although these finding contain a great deal of useful information, they should be considered as suggestive rather than conclusive.

A. Responses Provided by Service Consumers

Thirty-three persons with mental retardation were interviewed, 24 of whom are served in community programs while nine are served in institutions. Figure 7 displays the responses of those in community programs and Figure 8 shows the responses of state school residents. Key findings to consider:

- Review of the responses provided by consumers show that these persons can respond satisfactorily to questions regarding their life circumstances and preferences. Response biases (e.g., answering "yes" or "no" to all questions) are not apparent, as evidenced by significant changes in the distribution of responses by question.

These findings are consistent with other recent studies that show that service consumers can provide much useful information regarding the services they receive, given properly worded questions. If anything, these findings suggest that consumers were not fully utilized, since the questions they were asked generally sought descriptive information and avoided more sensitive issues (e.g., satisfaction with current day programs and other services received).

- Consumers indicated a willingness to learn the skills they are being taught. Review of their responses shows that a wide range of skills are taught and that a variety of vocational tasks are pursued. A minority of consumers, however, indicate that they were being taught how to participate in a job interview. Most consumers (17 of 23 valid responses) across community and institution settings professed a continued desire to learn additional skills.

- Consumers responded in ways that suggest that they are satisfied with the services they receive and with their life circumstances.

  * 26 of 27 consumers overall (six consumers did not respond) indicated that they received a paycheck for their work and 22 of these persons felt that they were paid enough.

  * 25 of 27 consumers overall (six consumers did not respond) noted no trouble with staff and 26 of 26 responding consumers felt they had someone to talk to in the event of a problem;

  * 25 of 29 consumers overall (four did not respond) felt they had enough to do on weekends while 25 of 27 felt they had enough money to spend on weekends.

- One issue worth considering pertains to the locus of control in choosing what is done during the day. A slight majority of responding consumers in both community and institutional (14 of 21) indicated that they have little say over their activities.

RESPONSES GIVEN BY CONSUMERS (N=24)
--COMMUNITY PROGRAMS--

PROGRAM	QUESTION CONTENT	YES	NO	DON'T KNOW	MISSING
DAY ACTIVITY PROGRAMS	LEARN ABOUT MONEY?	10	8	0	6
	LEARN ABOUT TELLING TIME?	10	6	0	8
	LEARN ABOUT HOW TO DRESS?	13	2	0	9
	LEARN ABOUT SHOPPING?	12	5	0	7
	LEARN ABOUT CROSSING STREETS?	10	5	0	9
	LEARN ABOUT COOKING?	10	7	0	7
	LEARN ABOUT CLEANING?	14	2	0	8
	LEARN ABOUT USING THE TELEPHONE?	8	7	0	9
	WANT TO LEARN ABOUT OTHER THINGS?	10	1	0	13
WORKSHOP/ ON SITE PROGRAMS	ARE YOU DOING PIECEWORK?	13	4	2	5
	ARE YOU DOING ASSEMBLY WORK?	15	3	1	5
	ARE YOU DOING PACKAGING?	17	2	0	5
	CHECK TO SEE IF WORK IS OK?	16	3	0	5
	RECEIVE TRAIN FOR JOB INTERVIEWS?	7	10	2	5
	LEARN HOW TO DRESS FOR WORK?	15	4	0	5
	RECEIVE A PAYCHECK?	20	0	0	4
	ARE YOU PAID ENOUGH?	19	0	1	4
	DO YOU HOLD YOUR OWN MONEY?	16	4	0	4
CLIENTS IN ANY PROGRAM	CHOOSE WHAT IS DONE SOMETIMES?	10	11	0	3
	LEARNED SOMETHING NEW RECENTLY?	16	6	1	1
	LIKE WHAT YOU DO?	23	1	0	0
	EVER HAD A PROBLEM WITH STAFF?	2	20	0	2
	SOMEONE TO TALK WITH RE PROBLEMS?	21	0	0	3
	EVER HAD TROUBLE WITH FRIENDS?	7	17	0	0
	PROBLEMS USUALLY WORKED OUT?	21	0	0	3
	HAVE PLACE TO PUT BELONGINGS?	14	9	0	1
	EVER HAVE FIRE DRILLS	20	3	0	1
	KNOW WHAT TO DO IN FIRE DRILLS?	21	0	0	3
	GO INDEPENDENTLY TO GROCERY STORE?	15	9	0	0
	GO INDEPENDENTLY TO BANK?	12	12	0	0
	GO INDEPENDENTLY TO RESTAURANT?	14	9	0	1
	GO INDEPENDENTLY TO HAIR SALON?	10	12	0	2
	GO INDEPENDENTLY TO MOVIES?	7	15	0	2
	GO INDEPENDENTLY TO WORK TO HOME?	5	15	0	4
	WOULD LIKE TO LEARN MORE?	13	4	0	7
	HAVE AN ISP?	23	0	0	1
	GO TO ISP MEETINGS?	22	2	0	0
	HAVE ENOUGH TO DO ON WEEKENDS?	21	0	3	0
	ENOUGH MONEY TO SPEND ON WEEKENDS?	20	2	0	2

OTHER TOPICS OF NOTE FROM CONSUMERS (N=24)
--COMMUNITY PROGRAMS--

QUESTION CONTENT	RESPONSE OPTION	NUMBER
DAY PROGRAM TYPE ATTENDED	DAY HABILITATION	4
	WORK ACTIVITY	1
	SHELTERED EMPLOY	8
	SUPPORTED EMPLOY	5
	MULTIPLE	4
	MISSING RESPONSE	1
IF LUNCH IS EATEN AT PROGRAM, IS IT	MADE FOR CLIENT?	5
	MADE BY CLIENT?	17
	SERVED AT PROGRAM?	1
	SERVED IN DINING ROOM?	0
	MISSING RESPONSE	1
WHAT DO YOU DO AT LUNCH TIME?	GO OUT TO LUNCH	4
	STAY AT PROGRAM & EAT	18
	STAY AT PROGRAM & COOK	0
	ALL OF ABOVE	4
	NONE OF ABOVE	0
WHAT DO YOU DO AT NIGHT?	WATCH TELEVISION	23
	VISIT FRIENDS	13
	GO TO MOVIES	10
	GO TO PARTIES	10
	MAKE LUNCH	15
	GO OUT TO DINNER	13
	DO OTHER THINGS	16

Figure 7: Responses Given by Consumers --Community Programs

RESPONSES GIVEN BY CONSUMERS (N=9)
--INSTITUTION PROGRAMS--

PROGRAM	QUESTION CONTENT	YES	NO	DON'T KNOW	MISSING
DAY ACTIVITY PROGRAMS	LEARN ABOUT MONEY?	9	0	0	0
	LEARN ABOUT TELLING TIME?	9	0	0	0
	LEARN ABOUT CLOTHES?	7	0	1	1
	LEARN ABOUT SHOPPING?	0	1	0	8
	LEARN ABOUT CROSSING STREETS?	7	2	0	0
	LEARN ABOUT DIFFERENT FOODS?	5	2	0	2
	LEARN ABOUT CLEANING?	7	0	0	2
	LEARN ABOUT USING THE TELEPHONE?	6	1	0	2
	WANT TO LEARN ABOUT OTHER THINGS?	5	1	2	1
WORKSHOP/ ON SITE PROGRAMS	ARE YOU DOING PIECEWORK?	5	1	0	3
	ARE YOU DOING ASSEMBLY WORK?	6	0	0	3
	ARE YOU DOING PACKAGING?	5	1	0	3
	ARE YOU BUILDING THINGS?	1	5	0	3
	LEARN ABOUT COLORS?	6	0	0	3
	LEARN ABOUT SHAPES?	4	1	1	3
	LEARN TO BRUSH YOUR TEETH?	5	0	1	3
	CHECK TO SEE IF WORK IS OK?	6	0	0	3
	RECEIVE TRAIN FOR JOB INTERVIEWS?	2	4	0	3
	LEARN HOW TO DRESS FOR WORK?	5	1	0	3
	RECEIVE A PAYCHECK?	6	1	0	2
	ARE YOU PAID ENOUGH?	3	2	1	3
	DO YOU HOLD YOUR OWN MONEY?	7	0	0	2
CLIENTS IN ANY PROGRAM	CHOOSE WHAT IS DONE SOMETIMES?	2	3	0	4
	LEARNED SOMETHING NEW RECENTLY?	1	3	1	4
	LIKE WHAT YOU DO?	5	1	0	2
	EVER HAD A PROBLEM WITH STAFF?	0	5	0	4
	SOMEONE TO TALK WITH RE PROBLEMS?	5	0	0	4
	EVER HAD TROUBLE WITH FRIENDS?	3	2	0	4
	PROBLEMS USUALLY WORKED OUT?	4	0	0	5
	HAVE PLACE TO PUT BELONGINGS?	6	1	0	3
	EVER HAVE FIRE DRILLS	6	2	0	1
	KNOW WHAT TO DO IN FIRE DRILLS?	7	0	0	2
	GO INDEPENDENTLY TO GROCERY STORE?	2	4	0	3
	GO INDEPENDENTLY TO BANK?	3	2	0	4
	GO INDEPENDENTLY TO RESTAURANT?	3	2	0	4
	GO INDEPENDENTLY TO HAIR SALON?	4	2	0	3
	GO INDEPENDENTLY TO CANTEEN?	4	1	0	3
	GO INDEPENDENTLY TO RECREATION?	2	2	0	5
	GO INDEPENDENTLY TO MOVIES?	2	3	0	4
	GO INDEPENDENTLY TO WORK TO HOME?	2	0	0	7
	WOULD LIKE TO LEARN MORE?	4	2	0	3
	HAVE AN ISP?	5	1	1	2
	GO TO ISP MEETINGS?	4	2	1	3
	HAVE ENOUGH TO DO ON WEEKENDS?	4	0	1	4
	ENOUGH MONEY TO SPEND ON WEEKENDS?	5	0	0	4

OTHER TOPICS OF NOTE FROM CONSUMERS (N=9)
--INSTITUTION PROGRAMS--

QUESTION CONTENT	RESPONSE OPTION	NUMBER
TYPE OF DAY PROGRAM ATTENDED	DAY HABILITATION	0
	WORK ACTIVITY	3
	SHELTERED EMPLOY	2
	EMPLOY ON GROUNDS	1
	MULTIPLE	1
	MISSING RESPONSE	2
IF LUNCH IS EATEN AT PROGRAM, IS IT	MADE FOR CLIENT?	2
	MADE BY CLIENT?	1
	SERVED AT PROGRAM?	0
	SERVED IN DINING ROOM?	2
	MISSING RESPONSE	4
WHAT DO YOU DO AT LUNCH TIME?	GO OUT TO LUNCH	2
	STAY AT PROGRAM & EAT	2
	OTHER ARRANGEMENT	2
	ALL OF ABOVE	1
	MISSING RESPONSE	2
WHAT DO YOU DO AT NIGHT?	WATCH TELEVISION	6
	VISIT FRIENDS	4
	GO TO MOVIES	3
	GO TO PARTIES	2
	MAKE LUNCH	1
	RECREATION BUILDING	3
	PLAY BINGO	3
	GO OUT TO DINNER	5
	DO OTHER THINGS	3

Figure 8: Responses Given by Consumers --Institution Programs

B. Responses Provided by Family Members

Thirty-eight family members were interviewed, 30 whose relatives attended community programs and eight whose relatives lived in state schools. Figure 9 displays responses provided by community family members, while Figure 10 shows those of state school family members.

Key findings to consider:

- Regardless of setting, family members are generally very satisfied with the services received by their members with mental retardation. Note that:

  * 27 of 36 responding family members believe the programs their member with mental retardation receives are "valuable," though the responses of state school parents are far less conclusive with only four of eight indicating that the programs are valuable;

  * 29 of 45 responding family members indicated that they are "highly" satisfied with the program their relative receives, while only four noted "low" satisfaction;

  * 36 of the 36 family members responding noted that they would recommend the program to others.

- Family members appeared to be adequately informed regarding the programs their relatives receive, noting skills instruction in a variety of areas, overall understanding on how paychecks are determined, and the frequecny of Individual Service Plan meetings.

- Two apparent trouble areas include recreation and transportation. Note that:

  * 14 of 33 responding family members indicated that problems exist regarding the transport of their family member with mental retardation to and from activities; and

  * 15 of 32 responding families felt that the availability of recreational activities is inadequate. Review of information regarding the social activities undertaken by persons with mental retardation appears to support this concern, given that most consumers "never" or "hardly ever" participate in the activities listed.

RESPONSES FROM FAMILY MEMBERS (N=30)
(COMM PROGRAMS)

PROGRAM	QUESTION CONTENT	YES	NO	DON'T KNOW	MISSING
CLIENTS IN ANY DAY PROGRAM	IS A PROGRAM VISIT VALUABLE?	23	5	0	2
	DO STAFF WELCOME COMMENTS?	29	0	1	0
	IS IT APPROPRIATE TO VISIT PROGRAMS?	24	3	2	1
	VISITED PROGRAM WHILE CLIENTS WORKING?	21	5	0	4
	ARE CLIENT'S SKILLS FULLY UTILIZED?	22	2	3	3
	DO STAFF UNDERSTAND WHAT MOTIVATES CLIENT?	27	1	1	1
	DOES CLIENT RECEIVE A PAY CHECK?	19	8	0	3
	DO PARENTS KNOW HOW PAY IS DETERMINED?	17	1	3	9
	ARE THERE ANY PROBLEMS WITH PAY?	3	18	0	9
	ARE THERE PROBLEMS WITH TRANSPORTATION?	12	15	1	2
	ARE THERE PROBLEMS WITH PERSONAL BELONGINGS?	4	24	2	0
	ARE THERE PROBLEMS WITH LUNCH?	2	27	1	0
	WOULD PARENT RECOMMEND PROGRAM TO OTHERS?	29	0	0	1
	ADEQUATE SOCIAL RECREATIONAL ACTIVITIES?	13	13	0	4
CLIENTS IN DAY HABILIT PROGRAM	CLIENT RECEIVES TRAINING IN DAILY LIV SKILLS?	17	2	0	11
	CLIENT RECEIVES TRAINING IN COMMUNITY ACCESS?	11	3	4	12
	CLIENT RECEIVES TRAINING IN SELF-CARE SKILLS?	12	5	0	13
	CLIENT RECEIVES TRAINING IN VOCATIONAL TASKS?	13	2	1	14
	DOES CLIENT RECEIVE A PAYCHECK?	13	4	0	13
	PREPARED FOR VOCATIONALLY ORIENTED SETTING?	12	3	1	9
CLIENTS IN WORK SHOPS & OTHER PROGRAMS	RECEIVES TRAINING IN DAILY WORK SKILLS?	17	1	0	12
	RECEIVES TRAINING IN VARIETY OF WORK TASKS?	11	3	3	13
	RECEIVES TRAINING IN PREPARING JOB APPLICAT?	4	9	3	14
	RECEIVES TRAINING IN GOING ON INTERVIEWS?	3	11	2	14
	RECEIVES TRAINING IN ON SITE WORK TASKS?	7	8	1	14
	RECEIVES TRAINING IN PROPER DRESS/APPEARANCE?	12	3	0	15

OTHER FAMILY RESPONSES
(COMM PROGRAMS) (N=30)

QUESTION CONTENT	RESPONSE OPTIONS	NUMBER
HOW OFTEN ARE ISP MEETINGS HELD?	EVERY 3 MONTHS	6
	EVERY 6 MONTHS	5
	ONCE A YEAR	14
	DON'T KNOW	1
	MISSING RESPONSE	4
OVERALL PROGRAM SATISFACTION?	HIGH	24
	MODERATE	4
	LOW	2
	MISSING RESPONSE	0
WHO PAYS FOR CLIENT SOCIAL ACTIVITIES?	CONSUMER	17
	STATE FUNDED	0
	FAMILY	0
	OTHER	0
	MULTIPLE SOURCES	10
	MISSING RESPONSE	3

SOCIAL ACTIVITIES UNDERTAKEN INDEPENDENTLY:	NEVER	HARDLY EVER	RARELY	OFTEN	VERY FREQUENT	MISSING DATA
GO TO DANCES/PARTIES	7	0	9	8	2	4
GO BOWLING	7	1	5	6	5	6
GO TO MOVIES	8	2	10	4	0	6
ATTEND SPORT EVENTS	13	0	3	6	1	7
ATTEND SOCIAL CLUBS	14	1	2	2	4	7
GO OUT TO DINNER	2	1	3	7	11	6
OTHER ACTIVITIES	2	1	2	2	2	21

ACTIVITIES UNDERTAKEN AT NIGHT	YES	NO	MISSING DATA
WATCH TELEVISION	22	4	4
VISIT FRIENDS	11	16	3
MAKE LUNCH	13	14	3
USE THE TELEPHONE	15	12	3
GO OUT TO DINNER	18	9	3
OTHER ACTIVITIES	17	10	3

SOCIAL ACTIVITIES UNDERTAKEN WITH STAFF	NEVER	HARDLY EVER	RARELY	OFTEN	VERY FREQUENT	MISSING DATA
GO TO DANCES/PARTIES	8	1	2	2	0	17
GO BOWLING	9	1	1	1	2	16
GO TO MOVIES	8	2	2	0	1	17
ATTEND SPORT EVENTS	9	1	2	1	0	17
ATTEND SOCIAL CLUBS	7	1	2	1	0	19
GO OUT TO DINNER	6	1	2	1	4	16
OTHER ACTIVITIES	5	3	1	1	2	18

Figure 9: Responses Given by Family Members --Community

Figure 10: Responses Given by Family Members --Institutions

RESPONSES FROM FAMILY MEMBERS (N=8)
--STATE SCHOOLS--

PROGRAM	QUESTION CONTENT	YES	NO	DON'T KNOW	MISSING
CLIENTS IN ANY DAY PROGRAM	IS A PROGRAM VISIT VALUABLE?	4	4	0	0
	DO STAFF WELCOME COMMENTS?	7	1	0	0
	IS IT APPROPRIATE TO VISIT PROGRAMS?	5	3	0	0
	VISITED PROGRAM WHILE CLIENTS WORKING?	6	2	0	0
	ARE CLIENT'S SKILLS FULLY UTILIZED?	7	0	0	1
	DO STAFF UNDERSTAND WHAT MOTIVATES CLIENT?	5	1	2	0
	DOES CLIENT RECEIVE A PAY CHECK?	3	4	0	1
	DO PARENTS KNOW HOW PAY IS DETERMINED?	1	0	1	6
	ARE THERE ANY PROBLEMS WITH PAY?	0	3	0	5
	ARE THERE PROBLEMS WITH TRANSPORTATION?	2	3	0	3
	ARE THERE PROBLEMS WITH PERSONAL BELONGINGS?	3	4	0	1
	ARE THERE PROBLEMS WITH LUNCH?	3	3	1	1
	WOULD PARENT RECOMMEND PROGRAM TO OTHERS?	7	0	0	1
	ADEQUATE SOCIAL RECREATIONAL ACTIVITIES?	2	4	1	1
CLIENTS IN DAY HABILIT PROGRAM	CLIENT RECEIVES TRAINING IN DAILY LIV SKILLS?	8	0	0	0
	CLIENT RECEIVES TRAINING IN COMMUNITY ACCESS?	3	2	2	1
	CLIENT RECEIVES TRAINING IN SELF-CARE SKILLS?	7	1	0	0
	CLIENT RECEIVES TRAINING IN VOCATIONAL TASKS?	5	3	0	0
	DOES CLIENT RECEIVE A PAYCHECK?	3	3	1	1
	PREPARED FOR VOCATIONALLY ORIENTED SETTING?	5	1	1	1
CLIENTS IN WORK SHOPS & OTHER PROGRAMS	RECEIVES TRAINING IN DAILY WORK SKILLS?	3	0	0	5
	RECEIVES TRAINING IN VARIETY OF WORK TASKS?	3	0	0	5
	RECEIVES TRAINING IN PREPARING JOB APPLICAT?	0	2	1	5
	RECEIVES TRAINING IN GOING ON INTERVIEWS?	0	2	0	6
	RECEIVES TRAINING IN ON SITE WORK TASKS?	0	2	0	6
	RECEIVES TRAINING IN PROPER DRESS/APPEARANCE?	1	2	0	5

OTHER FAMILY RESPONSES (N=8)
--STATE SCHOOLS--

QUESTION CONTENT	RESPONSE OPTIONS	NUMBER
HOW OFTEN ARE ISP MEETINGS HELD?	EVERY 3 MONTHS	1
	EVERY 6 MONTHS	1
	ONCE A YEAR	6
	DON'T KNOW	0
	MISSING RESPONSE	0
OVERALL PROGRAM SATISFACTION?	HIGH	5
	MODERATE	2
	LOW	0
	MISSING RESPONSE	1
WHO PAYS FOR CLIENT SOCIAL ACTIVITIES?	CONSUMER	7
	STATE FUNDED	0
	FAMILY	0
	OTHER	0
	MULTIPLE SOURCES	1
	MISSING RESPONSE	0

SOCIAL ACTIVITIES UNDERTAKEN INDEPENDENTLY	NEVER	HARDLY EVER	RARELY	OFTEN	VERY FREQUENT	MISSING DATA
GO TO DANCES/PARTIES	6	0	0	0	1	1
GO BOWLING	6	0	0	0	0	2
GO TO MOVIES	5	0	0	0	1	2
ATTEND SPORT EVENTS	5	1	0	1	0	1
ATTEND SOCIAL CLUBS	6	0	0	0	1	1
GO OUT TO DINNER	6	0	0	0	1	1
OTHER ACTIVITIES	5	0	0	0	0	3

SOCIAL ACTIVITIES UNDERTAKEN WITH STAFF	NEVER	HARDLY EVER	RARELY	OFTEN	VERY FREQUENT	MISSING DATA
GO TO DANCES/PARTIES	0	1	1	1	1	4
GO BOWLING	1	0	0	1	2	4
GO TO MOVIES	1	1	0	2	0	4
ATTEND SPORT EVENTS	1	1	1	1	0	4
ATTEND SOCIAL CLUBS	2	0	0	1	1	4
GO OUT TO DINNER	0	1	1	2	0	4
OTHER ACTIVITIES	0	1	0	0	0	7

C. Responses Provided by Members of Citizen Boards

Thirty members of community agency boards of directors or state school parent groups were interviewed, 27 of these serving on community boards. Figures 11 and 12 display the responses offered by these persons.

Key findings to consider:

- Review of the responses suggest a general satisfaction with the level of participation board members are accorded and with how programs are operated;
- Board members generally participate in a range of activities regarding the review of program activities and public relations;
- 21 of 27 responding board members note that the present level of funding for programs is insufficient;
- 20 of 27 respondents believe that families have difficulty understanding how to access day services for their family member; and
- 11 of the 30 respondents noted that they had no involvement with the family members of service consumers. Though not alarming, the level of such involvement may seem low to some.

RESPONSES GIVEN BY BOARD MEMBERS (N=27)
--COMMUNITY PROGRAMS--

QUESTION CONTENT	ALWAYS	MOST OF TIME	RARELY	NEVER	MISSING RESPONSE
CLEAR CHANNELS OF COMMUNICATION?	23	2	0	0	2
SUGGESTIONS RESPONDED TO IN WRITING?	13	3	4	4	3
ADMINISTRATION ATTENDS BOARD MEETINGS?	26	0	1	0	0
ADEQUATE TIME GIVEN FOR BOARD INPUT?	25	1	0	0	1

QUESTION CONTENT	YES	NO	DON'T KNOW	MISSING RESPONSE
BOARD MEETINGS GENERALLY PRODUCTIVE?	27	0	0	0
ARE YOU INVOLVED WITH FAMILY MEMBERS?	15	11	1	0
THINK FAMILIES ARE GENERALLY PLEASED?	19	1	1	1
FAMILIES HAVE PROBLEMS ACCESSING PROGS?	20	5	0	2
INVOLVED WITH AGENCY/PROGRAM DECISIONS?	22	5	0	0
REVIEW PROGRAM POLICIES?	22	0	0	5
REVIEW STANDARDS AND GUIDELINES?	19	8	0	0
TAKE PART IN PROGRAM QUALITY CONTROL?	18	9	0	0
APPROPRIATE PROGS TO MEET CLIENT NEEDS?	20	5	0	2
INVOLVED WITH AGENCY BUDGET PROCESS?	25	2	0	0
IS FUNDING SUFFICIENT FOR AGENCY?	6	18	0	3
UNDERSTAND STATE LEGISLATIVE PROCESS?	22	2	0	2
BEEN INVOLVED WITH ADVOCACY EFFORTS?	22	4	0	1

OTHER TOPICS OF NOTE -- BOARD MEMBERS (N=27)
--COMMUNITY PROGRAMS--

QUESTION CONTENT	RESPONSE OPTION	NUMBER
MONITORING ACTIVITIES BOARD IS INVOLVED WITH	REVIEW OF EVAL RESULTS	22
	REVIEW FOLLOW-UP REPORTS	23
	PARTIC ON COMMUN MONITOR TEAM	9
	PARTIC ON STATE MONITOR TEAM	0
PUBLIC RELATION ACTIVITIES BOARD IS INVOLVED WITH	DISSEMINATE MATERIALS	15
	DEVELOP RESOURCE DIRECTORY	7
	RADIO AND TV BROADCASTS	10
	OTHER	0
ACTIVITIES TO IMPROVE QUALITY OF LIFE WHICH BOARD IS INVOLVED WITH	ORGANIZE LOCAL RECREA EVENTS	2
	FUND RAISING	4
	OTHER ACTIVITIES	2
	NO ACTIVITIES	1
	MULTIPLE ACTIVITIES	18

Figure 11: Responses Given by Community Board Members

Figure 12: Responses Given by Members of Institution Parent Groups

RESPONSES GIVEN BY BOARD MEMBERS (N=3)
--INSTITUTION PROGRAMS--

QUESTION CONTENT	ALWAYS	MOST OF TIME	RARELY	NEVER	MISSING RESPONSE
CLEAR CHANNELS OF COMMUNICATION?	1	2	0	0	0
SUGGESTIONS RESPONDED TO IN WRITING?	0	3	0	0	0
ADMINISTRATION ATTENDS BOARD MEETINGS?	0	2	0	1	0
ADEQUATE TIME GIVEN FOR BOARD INPUT?	3	0	0	0	0

QUESTION CONTENT	YES	NO	DON'T KNOW	MISSING RESPONSE
BOARD MEETINGS GENERALLY PRODUCTIVE?	3	0	0	0
ARE YOU INVOLVED WITH FAMILY MEMBERS?	3	0	0	0
THINK FAMILIES ARE GENERALLY PLEASED?	2	1	0	0
FAMILIES HAVE PROBLEMS ACCESSING PROGS?	3	0	0	0
INVOLVED WITH AGENCY/PROGRAM DECISIONS?	2	1	0	0
REVIEW PROGRAM POLICIES?	2	0	0	1
REVIEW STANDARDS AND GUIDELINES?	0	2	0	0
TAKE PART IN PROGRAM QUALITY CONTROL?	0	3	0	0
APPROPRIATE PROGS TO MEET CLIENT NEEDS?	2	1	0	0
INVOLVED WITH AGENCY BUDGET PROCESS?	0	3	0	0
IS FUNDING SUFFICIENT FOR AGENCY?	0	0	0	0
UNDERSTAND STATE LEGISLATIVE PROCESS?	2	1	0	0
BEEN INVOLVED WITH ADVOCACY EFFORTS?	2	1	0	0

OTHER TOPICS OF NOTE -- BOARD MEMBERS (N=3)
--INSTITUTION PROGRAMS--

QUESTION CONTENT	RESPONSE OPTION	NUMBER
MONITORING ACTIVITIES BOARD IS INVOLVED WITH	REVIEW OF EVAL RESULTS	2
	REVIEW FOLLOW-UP REPORTS	2
	PARTIC ON COMMUN MONITOR TEAM	0
	PARTIC ON STATE MONITOR TEAM	2
PUBLIC RELATION ACTIVITIES BOARD IS INVOLVED WITH	DISSEMINATE MATERIALS	3
	DEVELOP RESOURCE DIRECTORY	0
	RADIO AND TV BROADCASTS	0
	OTHER	1
ACTIVITIES TO IMPROVE QUALITY OF LIFE WHICH BOARD IS INVOLVED WITH	ORGANIZE LOCAL RECREA EVENTS	0
	FUND RAISING	1
	OTHER ACTIVITIES	0
	NO ACTIVITIES	0
	MULTIPLE ACTIVITIES	2

D. Responses Provided by Administrative Staff

Fifty-eight persons serving in program administrative capacities were interviewed, 46 of whom are employed by community agencies and 12 by state schools. Figures 13 and 14 display their responses.

Key findings to consider:

- Overall, administrative staff are less complimentary of the services provided than others interviewed in this project. Note that:

  * the majority of community-based vendor administrative staff (23 of 40 respondents) believe that there is an absence of opportunities for consumers to move onto less restrictive settings. In contrast, only two of 12 state school administrators noted such inadequate opportunity. These findings suggest that the problem is more apparent within community settings.

  * The majority of community-based vendor administrators (29 of 41 respondents) noted that supports for families providing home care are insufficient. Again, their state school counterparts were not in agreement, with five of six respondents noting that supports for families were adequate. However, this finding ought not be misinterpreted. Community staff likely were referring to supports offered to families who provide home care, while state school staff were considering the adequacy of supports provided families whose children live out-of-home in state school residences.

  * the availability of recreational opportunity for consumers was viewed by nearly half the respondents (22 of 47 overall) as a problem, regardless of setting.

- To assure that human rights are protected, nearly all respondents indicated the presence of a human rights committee (53 of 57 respondents overall) and ongoing staff training regarding human rights (47 of 57 respodnents overall);

- Most administrators (46 of 58 respondents overall) felt that to protect the human rights of consumers additional policy is NOT needed, but that additional staff training (41 of 58 respondents overall) and technical consultation (34 of 58 respondents overall) would be helpful.

- Administrators of both community and state school programs complained about the staffing problems they endure, with 44 of the 58 respondents overall noting a problem.

- Major factors contributing to staff problems did vary some between community and state school programs. Among community vendor administrators 33 of 34 noted low staff pay as a

contributing factor while only four of 10 state school administrators noted this factor. Likewise, while 30 of 34 community vendor administrators indicated a problem with finding appropriate staff, only five of 10 state school administrators noted this factor.

However, there was agreement between administrators on several other factors contributing to staff problems, including insufficient staff to client ratios and behavior problems displayed by consumers;

- Not shown in Figures 13 and 14 are the staff turnover rates among programs. There figures were computed based on responses to a series of questions on the number of staff employed by agencies and the number quitting their jobs over the past 12 months. Note that:

  * Based on responses provided by the 46 community based respondents, the turnover rate among direct care staff in their day programs averaged 60%, ranging from 0 to 153%.

  * Among state school programs, the turnover rate for direct care staff working in day programs averaged 31%, ranging from 0% to 125%.

Figure 13: Responses Given by Administrative Staff --Community Vendors

QUESTIONS ASKED OF COMMUNITY ADMINISTRATIVE STAFF
(N=46)

QUESTION ASKED	YES	NO	DON'T KNOW	MISSING
ARE THERE ADEQUATE OPPORTUNITIES FOR CLIENTS TO MOVE ON?	17	23	1	5
ARE THERE ADEQUATE SUPPORT SERVICES FOR FAMILIES?	11	29	1	5
ARE THERE ADEQUATE SOCIAL/RECREA ACTIVITIES FOR CLIENTS	22	18	4	2
TO ASSURE RESPECT OF HUMAN RIGHTS WHICH OF THE FOLLOWING OCCURS?				
-HUMAN RIGHTS COMM ESTABLISHED?	42	3	0	1
-ONGOING TRAINING ON RIGHTS?	39	6	0	1
-OTHER TACTICS USED	11	35	0	0
HOW CAN WE BETTER ADDRESS THE ISSUE OF PROTECTING HUMAN RIGHTS?				
-ADDITIONAL TRAIN & TECH ASST	32	14	0	0
-ESTABLISH ADDITIONAL POLICY	7	39	0	0
-CONSULTATION SERVICES FOR PROGS	24	22	0	0
-OTHER TACTICS	16	30	0	0
ARE ALL YOU PROGRAMS LICENSED?	35	8	0	3
DO YOU EXPERIENCE STAFF PROBLEMS?	34	11	0	1
WHAT FACTORS MOST CONTRIBUTE TO STAFF PROBLEMS?				
-INTENSITY OF WORK	25	9	0	12
-LOW SALARIES	33	1	0	12
-LEVEL OF CLIENT DISABILITY	13	21	0	12
-BEHAVIOR PROBLEMS	17	17	0	12
-INSUFFICIENT STAFFING	20	14	0	12
-HARD TO FIND APPROPRIATE STAFF	30	4	0	12
-LACK OF STAFF TRAINING	1	2	0	43
-OTHER REASONS	5	27	0	14
DO YOU HAVE WRITTEN PERSONNEL POLICIES REGARDING				
-STAFF QUALIFICATIONS?	43	0	0	3
-STAFF BENEFITS?	43	0	0	3
-VACATION TIME?	43	0	0	3
-EDUCATION?	42	0	1	3
-HIRING PRACTICES?	41	1	1	3

Figure 14: Responses Given by Administrative Staff --Institutions

QUESTIONS ASKED OF INSTITUTION ADMINISTRATIVE STAFF
(N=12)

QUESTION ASKED	YES	NO	DON'T KNOW	MISSING
ARE THERE ADEQUATE OPPORTUNITIES FOR CLIENTS TO MOVE ON?	10	2	0	0
ARE THERE ADEQUATE SUPPORT SERVICES FOR FAMILIES?	5	1	4	2
ARE THERE ADEQUATE SOCIAL/RECREA ACTIVITIES FOR CLIENTS	7	4	1	0
TO ASSURE QUALITY OF LIFE WHICH OF THE FOLLOWING OCCURS?				
-HUMAN RIGHTS COMM ESTABLISHED?	11	1	0	0
-ONGOING TRAINING ON RIGHTS?	8	4	0	0
-OTHER TACTICS USED	4	8	0	0
HOW CAN WE BETTER ADDRESS THE ISSUE OF PROTECTING HUMAN RIGHTS?				
-ADDITIONAL TRAIN & TECH ASST	9	3	0	0
-ESTABLISH ADDITIONAL POLICY	5	7	0	0
-CONSULTATION SERVICES FOR PROGS	10	2	0	0
-OTHER TACTICS	4	8	0	0
ARE ALL YOU PROGRAMS LICENSED?	5	3	1	3
DO YOU EXPERIENCE STAFF PROBLEMS?	10	2	0	0
WHAT FACTORS MOST CONTRIBUTE TO STAFF PROBLEMS?				
-INTENSITY OF WORK	5	5	0	0
-LOW SALARIES	4	6	0	0
-LEVEL OF CLIENT DISABILITY	7	3	0	0
-BEHAVIOR PROBLEMS	7	3	0	0
-INSUFFICIENT STAFFING	7	3	0	0
-HARD TO FIND APPROPRIATE STAFF	5	5	0	0
-LACK OF STAFF TRAINING	1	9	0	0
-OTHER REASONS	3	7	0	0
DO YOU HAVE WRITTEN PERSONNEL POLICIES REGARDING				
-STAFF QUALIFICATIONS?	12	0	0	0
-STAFF BENEFITS?	12	0	0	0
-VACATION TIME?	12	0	0	0
-EDUCATION?	12	0	0	0
-HIRING PRACTICES?	12	0	0	0

E. Responses Provided by Area Mental Retardation Coordinators

Eleven community Area Mental Retardation Coordinators were interviewed. Their responses are displayed in Figure 15. Key findings to consider:

- MR cooridnators, like administrative staff within service agencies, indicate a need for systems change in a variety of areas. Note that:
  - * All 11 suggest a need for developing specific program models in their area. Programs warranting further development include supported work, social-recreational services, and pre-vocational day programs;
  - * Ten of ten respondents note that consumers in day habilitation programs could benefit from work related instruction, but only one believed that these consumers were receiving the instruction they require;
  - * Nine of ten respondents noted that there are consumers residing in Medicaid funded facilities who cannot obtain Medicaid funded day services due to federal policies maintained by the Department of Public Welfare;
  - * Four of nine respondents felt that consumers were getting the therapeutic services they needed; and
- Most available programs are licensed.

QUESTION RESPONSES FROM MENTAL RETARDATION
MENT RET COORDINATORS (N=11)

QUESTION ASKED	YES	NO	DON'T KNOW	MISSING
PARTICULAR MODELS THAT NEED DEVELOPMENT IN YOUR AREA?	11	0	0	0
ARE MOST OF CLIENTS RECEIVING THE THERAPEUTIC SERVICES THEY NEED?	5	4	0	2
ARE THERE CLIENTS IN DAY SERVICE PROGS THAT CAN BENEFIT FROM WORK?	10	0	0	1
ARE THESE CLIENTS GETTING THE VOCATIONAL SERVICES THEY NEED?	1	8	1	1
ARE THERE CLIENTS IN MEDICAID FACIL! WHO CANNOT MEDICAID DAY HABIL?	9	1	1	0
WHICH OF THE FOLLOWING ROLES DO CITIZEN ADVOC PLAY IN YOUR AREA?				
-ON AREA/VENDOR BOARDS	10	1	0	0
-LINK COMMUNITY & AGENCY	7	4	0	0
-INDEPENDENT RESOURCE GROUP	6	5	0	0
-LOBBY FOR CHANGE IN LAWS...	5	6	0	0
-THER ROLES	3	8	0	0

QUESTION	RESPONSE OPTION	NUMBER
WHAT STATEMENT BEST REFLECTS HOW CLIENTS ARE PLACED INTO DAY PROGS	ALWAYS MATCHED	0
	USUALLY MATCHED	8
	SELDOM MATCHED	2
	NEVER MATCHED	0
	DESIGN SPECIFIC PROGS	0
	MISSING RESPONSE	1
WHAT PROGRAM MODELS ARE IN GREATEST NEED OF DEVELOPMENT?	SOCIO-RECREATIONAL	3
	PRE-VOCATIONAL DAY PROGS	3
	ON SITE WORK	4
	SHELTERED WORKSHOP	0
	BASIC SKILLS WORKSHP	0
	MORE THAN ONE	1

LICENSING AND MONITORING
MENT RET COORDINATORS (N=11)

PROGRAM TYPE	NUMBER PROGRAMS	MISSING	NUMBER LICENSED	MISSING	NUMBER WITH LIC DEFICIENT	MISSING
DAY ACTIVITY	17	2	12	3	3	3
DAY HABILITATION	5	4	2	5	1	6
WORK ACTIVITY	9	4	12	3	2	4
SHELTERED WORKSHOP	9	2	11	5	2	6
ON-SITE WORK	9	3	3	5	2	5
APPRENTICESHIP	0	7	1	6	0	8
RESPITE CARE	9	4	1	6	0	7
SPECIALIZED HOME CARE	3	6	0	8	0	8
OTHER	10	4	--	11	0	8

Figure 15: Responses Given by Area MR Coordinators

F. Comparison of Selected Responses

Several identical questions were asked of more than one type of respondent, allowing comparison of responses. Three such topic areas include: 1) satisfaction with the Individual Service Planning process, 2) program availability and overall adequacy, and 3) program monitoring. Figure 16 displays these areas and the sources of information that may be compared.

Figure 16: Source of Information by Topic Area

Source of Information	ISP Satisfaction	Program Avail./Adeq.	Program Monitoring
Community Programs			
1. Family Members	X		
2. Administrative Staff	X	X	X
3. Area Coordinators	X	X	X
State School Programs			
1. Family Members	X		
2. Administrative Staff	X	X	X

Figure 17 displays information regarding satisfaction with various aspects of the ISP process among persons involved with community programs, while Figure 18 presents similar information regarding state schools. Additionally, Figure 19 displays average levels of satisfaction with the ISP process by respondent type. As shown, overall there is great satisfaction with the ISP process.

Key observations:

- Family members appear more satisfied with the ISP process than the professionals questioned. For instance, among community programs, note that both MR coordinators and administrative staff are not as satisfied as family members with regard to ISP specifying the means of skills instruction or coordination bewteen day and residential programs.
- Satisfaction across various aspects of the ISP process varies by aspect and source of information. For instance, regarding

the participation of the family, most family members are highly satisfied (23 of 28 among community programs and 6 of 8 among state schools), while administrative staff are not so satisfied.

Likewise, while family members generally believe that realistic goals are set at ISP meetings (24 of 30 community family members and 4 of 8 state school members), professional staff are not as convinced.

- Scores to reflect the overall satisfaction with the ISP process were also calculated. Satisfaction on each of nine aspects of the ISP process were scored (2=high satisfaction, 1=moderate satisfaction, 0=low satisfaction) for each respondent to yield a "Total Satisfaction Score." Scores could range from 0 (lowest satisfaction) to 18 (highest satisfaction).

  Figure 19 shows the average satisfaction score by respondent type for community and state school respondents. As shown, parents appear more satisfied with the ISP process than are professionals, though all seem at least moderately satisfied. Unfortunately, consumers were not asked about their satisfaction with the ISP process.

Figure 17: ISP Satisfaction Comparison --Community

ISP SATISFACTION COMPARISON
COMMUNITY PROGRAMS

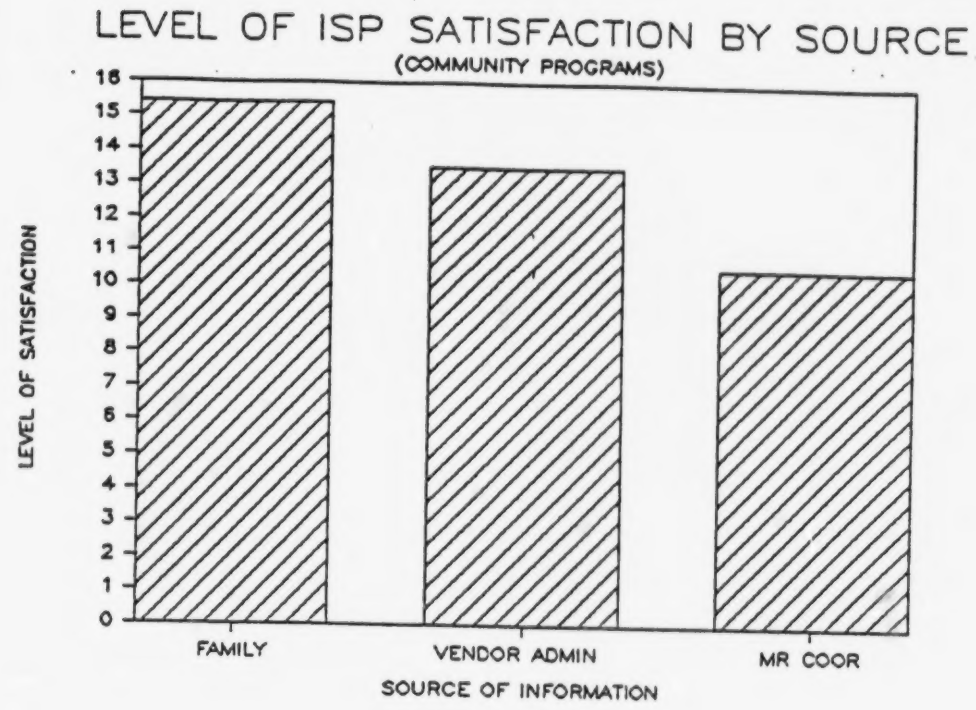
ISP COMPONENT	SOURCE	HIGH	MODERATE	LOW	MISSING	TOTAL
A. ACTIVE PARTICIPATION OF CLIENTS?	FAMILY	20	4	3	3	30
	MR COOR	5	5	1	0	11
	ADMIN STAFF	25	11	2	8	46
B. ACTIVE PARTIC OF PROFESSIONALS?	FAMILY	26	2	2	0	30
	MR COOR	7	3	1	0	11
	ADMIN STAFF	26	11	1	8	46
C. ACTIVE PARTICIPATION OF FAMILY?	FAMILY	23	4	1	2	30
	MR COOR	5	5	0	1	11
	ADMIN STAFF	14	21	4	7	46
D. ISP DOCUMENTS UNMET CLIENT NEEDS?	FAMILY	22	3	2	3	30
	MR COOR	7	1	3	0	11
	ADMIN STAFF	19	14	5	8	46
E. ISP DOCUMENTS REALISTIC GOALS?	FAMILY	24	3	3	0	30
	MR COOR	4	3	3	1	11
	ADMIN STAFF	26	10	2	8	46
F. ISP DOCUMENTS CONTENT OF INSTRUCT?	FAMILY	22	3	1	4	30
	MR COOR	6	3	2	0	11
	ADMIN STAFF	24	9	5	8	46
G. ISP DOCUMENTS MEANS OF INSTRUCION?	FAMILY	21	3	2	4	30
	MR COOR	3	5	3	0	11
	ADMIN STAFF	19	13	5	9	46
H. ISP DOCUMENTS COORDINATION BETWEEN DAY/RESID PROGRAMS?	FAMILY	11	2	3	14	30
	MR COOR	2	4	4	1	11
	ADMIN STAFF	6	18	12	10	46
I. ISP DOCUMENT EXIT/ENTRANCE CRITERIA?	FAMILY	13	4	2	11	30
	MR COOR	4	2	4	1	11
	ADMIN STAFF	18	10	6	12	46
	TOTALS	402	176	82	123	

Figure 18: ISP Satisfaction Comparison --Institutions

ISP SATISFACTION COMPARISON
(STATE SCHOOLS)

ISP COMPONENT	SOURCE	HIGH	MODERATE	LOW	MISSING	TOTAL
A. ACTIVE PARTICIPATION OF CLIENTS?	ADMIN STAFF	9	1	2	0	12
	FAMILY	5	0	1	2	8
B. ACTIVE PARTIC OF PROFESSIONALS?	ADMIN STAFF	9	3	0	0	12
	FAMILY	8	0	0	0	8
C. ACTIVE PARTICIPATION OF FAMILY?	ADMIN STAFF	1	2	0	9	12
	FAMILY	6	0	2	0	8
D. ISP DOCUMENTS UNMET CLIENT NEEDS?	ADMIN STAFF	8	4	0	0	12
	FAMILY	3	2	1	2	8
E. ISP DOCUMENTS REALISTIC GOALS?	ADMIN STAFF	6	6	0	0	12
	FAMILY	4	2	2	0	8
F. ISP DOCUMENTS CONTENT OF INSTRUCT?	ADMIN STAFF	4	7	1	0	12
	FAMILY	6	1	1	0	8
G. ISP DOCUMENTS MEANS OF INSTRUCION?	ADMIN STAFF	5	5	2	0	12
	FAMILY	2	3	1	2	8
H. ISP DOCUMENTS COORDINATION BETWEEN DAY/RESID PROGRAMS?	ADMIN STAFF	5	5	1	1	12
	FAMILY	4	2	1	1	8
I. ISP DOCUMENT EXIT/ENTRANCE CRITERIA?	ADMIN STAFF	5	4	3	0	12
	FAMILY	5	1	1	1	8
	TOTALS	95	48	19	18	

Figure 19: Total ISP Satisfaction Scores by Source



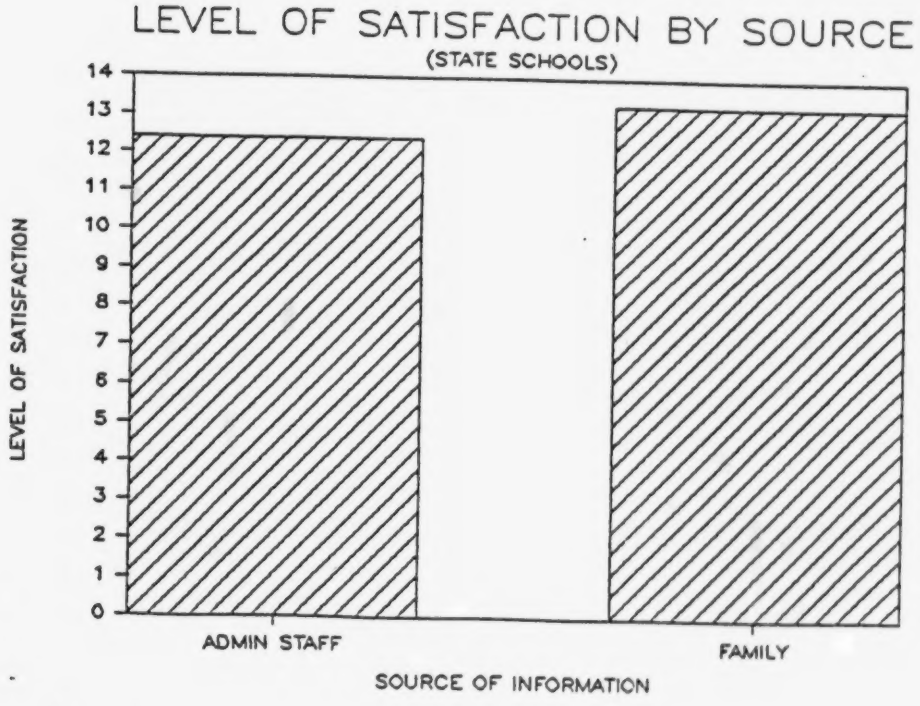


Figure 20 displays information secured from community based administrative staff and area MR coordinators on program availability and adequacy. Similarly, Figure 21 shows the same type of information collected from state school administrative staff.

Key observations include:

- Review of responses provided by community administrative and MR coordinators (Figure 20), reveals significant disagreement regarding the availability of programs and the number of consumers on waiting lists. Generally, community administrative staff note the existance of more programs and many more persons awaiting service than area MR coordinators;

- Regarding community programs, however, both administrators and MR coordinators note a need for every type of program listed. Certainly, the need varies by geographic area, given that some respondents indicate that the availability of some programs is very adequate. Yet, the need to expand existing service options to allow consumers opportunity to move between programs is clearly documented.

  Services most often noted as inadequate include family support programs, social-recreational programs, day activity and supported work.

- Regarding state schools (Figure 21), significant numbers of persons are listed as waiting for vocational services. Yet, the adequacy of service availability is often listed as "very adequate."

Figure 20: Program Availabilty and Adequacy --Community

PROGRAMS AVAILABLE AND OVERALL ADEQUACY
(MENT RET COORDINATORS (N=11)

PROGRAM TYPE	SPECIFIC PROGRAM	NUMBER OF PROGRAMS	MISSING	NUMBER WAITING	MISSING	ADEQUACY: VERY ADEQ	SUFFICIENT	INADEQUATE	MISSING
VOCATION PROGRAMS	DAY ACTIVITY	11	1	97	3	1	3	5	2
	DAY HABILITATION	1	2	57	4	1	1	6	3
	WORK ACTIVITY	8	1	17	5	2	1	4	4
	SHELTERED WORKSHOP	11	1	62	4	3	1	5	2
	ON-SITE WORK PROGRAM	8	1	5	9	1	3	6	1
	OTHER	63	4	--	11	1	0	0	10
FAMILY PROGRAMS	RESPITE CARE (IN HOME)	9	1	85	6	2	1	6	2
	RESPITE CARE (OUT OF HOME)	7	2	50	7	2	1	6	2
	RESPITE CARE (FACILITY BASED)	3	3	25	8	1	0	7	3
	SPECIALIZED HOME CARE	9	2	63	4	3	0	5	3
OTHER PROGRAMS	SOCIAL/RECREAT SERVICES (DMH)	4	1	0	10	1	1	6	3
	SOCIAL/RECREAT SERV (GENERIC)	7	5	--	11	1	3	5	2
	PARENT SUPPORT/ADVOCACY	12	2	--	11	2	1	4	4
	ACTIVE TREATMENT	--	11	--	11	0	0	0	11
	OTHER	1	10	--	11	0	0	0	11

PROGRAMS AVAILABLE AND OVERALL ADEQUACY
(COMMUNITY ADMIN STAFF (N=46)

PROGRAM TYPE	SPECIFIC PROGRAM	NUMBER OF PROGRAMS	MISSING	NUMBER WAITING	MISSING	ADEQUACY: VERY ADEQ	SUFFICIENT	INADEQUATE	MISSING
VOCATION PROGRAMS	DAY ACTIVITY	26	25	206	31	6	2	12	26
	DAY HABILITATION	12	34	157	37	5	0	4	37
	WORK ACTIVITY	18	29	87	36	6	3	5	32
	SHELTERED WORKSHOP	13	33	174	38	4	5	7	30
	ON-SITE WORK PROGRAM	31	31	202	34	4	6	5	31
	OTHER	1	45	---	---	0	0	1	45
FAMILY PROGRAMS	RESPITE CARE (IN HOME)	12	36	301	39	2	2	9	33
	RESPITE CARE (OUT OF HOME)	6	39	177	40	6	1	6	33
	RESPITE CARE (FACILITY BASED)	12	34	124	42	2	1	11	32
	SPECIALIZED HOME CARE	5	40	92	42	3	1	7	35
OTHER PROGRAMS	SOCIAL/RECREAT SERVICES (DMH)	7	37	160	41	3	4	7	32
	SOCIAL/RECREAT SERV (GENERIC)	---	---	---	---	5	2	8	31
	PARENT SUPPORT/ADVOCACY	7	37	154	42	9	2	11	24
	ACTIVE TREATMENT	6	43	---	---	1	0	0	45

Figure 21: Program Availability and Adequacy --Institutions

PROGRAMS AVAILABLE AND OVERALL ADEQUACY
(INSTIT ADMIN (N=12)

PROGRAM TYPE	SPECIFIC PROGRAM	NUMBER OF PROGRAMS	MISSING	NUMBER WAITING	MISSING	ADEQUACY VERY ADEQ	SUFFICIENT	INADEQUATE	MISSING
VOCATION PROGRAMS	DAY ACTIVITY	16	8	98	11	4	0	1	7
	DAY HABILITATION	---	12	---	12	1	0	0	11
	WORK ACTIVITY	3	9	116	9	4	0	1	7
	SHELTERED WORKSHOP	2	10	55	10	2	0	0	10
	ON-SITE WORK PROGRAM	2	11	35	11	2	1	0	9
	OTHER	---	12	20	9	1	1	1	9
FAMILY PROGRAMS	RESPITE CARE (IN HOME)	---	12	--	12	---	---	---	12
	RESPITE CARE (OUT OF HOME)	---	12	--	12	---	---	---	12
	RESPITE CARE (FACILITY BASED)	---	12	--	12	---	---	---	12
	SPECIALIZED HOME CARE	---	12	--	12	---	---	---	12
OTHER PROGRAMS	SOCIAL/RECREAT SERVICES (DMH)	1	11	58	11	2	0	0	10
	SOCIAL/RECREAT SERV (GENERIC)	---	12	--	12	1	0	0	11
	PARENT SUPPORT/ADVOCACY	---	12	--	12	---	---	---	12
	ACTIVE TREATMENT	1	11	--	12	2	0	0	10

Figure 22 displays information collected on program monitoring patterns within community programs, while Figure 23 presents similar data on state schools. Key observations:

- Programs surveyed use a variety of processes to monitor day and other non-residential services, including:
  - * Formal monitoring procedures developed by the Department of Mental Health; and
  - * Self monitoring practices developed internally by individual vendor agencies.
- Regardless of setting, the single most frequently used monitoring tactic involves the programs own resources ("self-monitoring").
- Within community programs, monitoring practices enacted by Department of Mental Health Area Offices are in widespread use and include:
  - * the DMH Quality Assurance Process: Review of a program using a particular monitoring tool developed by DMH;
  - * the Area Monitoring Process: Processes used are developed in each area (though existing practices are not necessarily standardized across areas). Their purpose is to determine whether vendors are meeting contract and other area requirements; and
  - * Independent Professional Review (IPR): A formal monitoring process based in the principles of normalization whereby DMH contracts with various professionals to evaluate specific agencies.

PROGRAM MONITORING PATTERNS
MENT RET COORDINATORS (N=11)

PROGRAM TYPE	SELF MONITOR	QUALITY ASURANCE	AREA MONITOR	IPR	CARF	OTHER	NONE	TOTAL
DAY ACTIVITY	6	3	7	6	3	0	0	25
DAY HABILITATION	3	0	0	3	1	1	0	8
WORK ACTIVITY	5	2	4	1	1	0	0	13
SHELTERED WORKSHOP	5	4	6	2	5	1	0	23
ON-SITE WORK PROGRAM	5	3	3	3	2	0	0	16
RESPITE CARE	6	4	6	2	0	1	0	19
SPECIALIZED HOME CARE	5	3	5	3	0	0	0	16
OTHER PROGRAMS	1	1	1	1	--	--	--	4
TOTALS	36	20	32	21	12	3	0	

PROGRAM MONITORING PATTERNS
COMMUNITY ADMIN STAFF (N=46)

PROGRAM TYPE	SELF MONITOR	QUALITY ASURANCE	AREA MONITOR	IPR	CARF	OTHER	NONE	TOTAL
DAY ACTIVITY	11	4	11	7	6	1	1	40
DAY HABILITATION	12	6	10	8	6	4	1	46
WORK ACTIVITY	8	7	11	7	6	4	1	43
SHELTERED WORKSHOP	13	5	10	7	9	3	1	47
ON-SITE WORK PROGRAM	6	3	6	3	3	4	0	25
RESPITE CARE	5	3	2	0	0	2	1	12
SPECIALIZED HOME CARE	2	2	3	0	0	1	0	8
OTHER PROGRAMS	1	0	1	0	0	0	0	2
TOTALS	58	30	54	32	30	19	5	

Figure 22: Program Monitoring --Community Programs

Figure 23: Program Monitoring --Institution Programs

PROGRAM MONITORING PATTERNS
INSTITUTION ADMIN (N=12)

PROGRAM TYPE	SELF MONITOR	QUALITY ASURANCE	AREA MONITOR	IPR	CARF	OTHER	NONE
DAY ACTIVITY	5	3	0	1	0	1	1
DAY HABILITATION	2	0	0	0	0	1	0
WORK ACTIVITY	4	2	0	0	0	3	1
SHELTERED WORKSHOP	3	1	0	0	0	3	0
ON-SITE WORK PROGRAM	4	2	0	1	1	2	0
RESPITE CARE	1	0	0	0	0	1	0
SPECIALIZED HOME CARE	0	0	0	0	0	0	0
OTHER PROGRAMS	0	0	0	0	0	0	0
TOTALS	19	8	0	2	1	11	2

IV. INTERPRETATION OF RESULTS

A. Conceptual Framework Used to Guide the Interpretation

A primary purpose of this project is to find ways to improve day and other non-residential services offered to persons with mental retardation in Massachusetts. The interviews completed provide a wealth of information to inform any discussion aimed at improving services. Given the range and mass of information collected, however, a conceptual framework, displayed in Figure 24, was developed to ease review of the information and to structure discussion.

As shown by Figure 24, given present conditions, the conceptual framework used to guide data review involves four major components:

- Service Planning and Delivery. The driving question within this component is simply:

  "Are consumers getting all they need?"

  Certainly, not all potential consumer needs suggested by this broadly stated question were examined through this project. Four relevant issues that were include:

  * Satisfaction with Individual Service Plans (ISPs). One intent of the ISP process is to bring together a team of persons involved and concerned with services needed by an individual consumer. The consumer him/herself is considered a key member of the team. Generally, team members are charged with assessing the consumer's needs, assuring that the consumer receives required services, and planning for the long term.

    How well the ISP process works is dependent on a variety of factors. In this project, satisfaction with the ISP process was examined. Specific components of the process were studied and an "overall satisfaction" score was computed. Moreover, because identical questions were asked of executive directors, parents and area mental retardation coordinators, comparison of responses across these persons is possible. Unfortunately, consumers were not asked

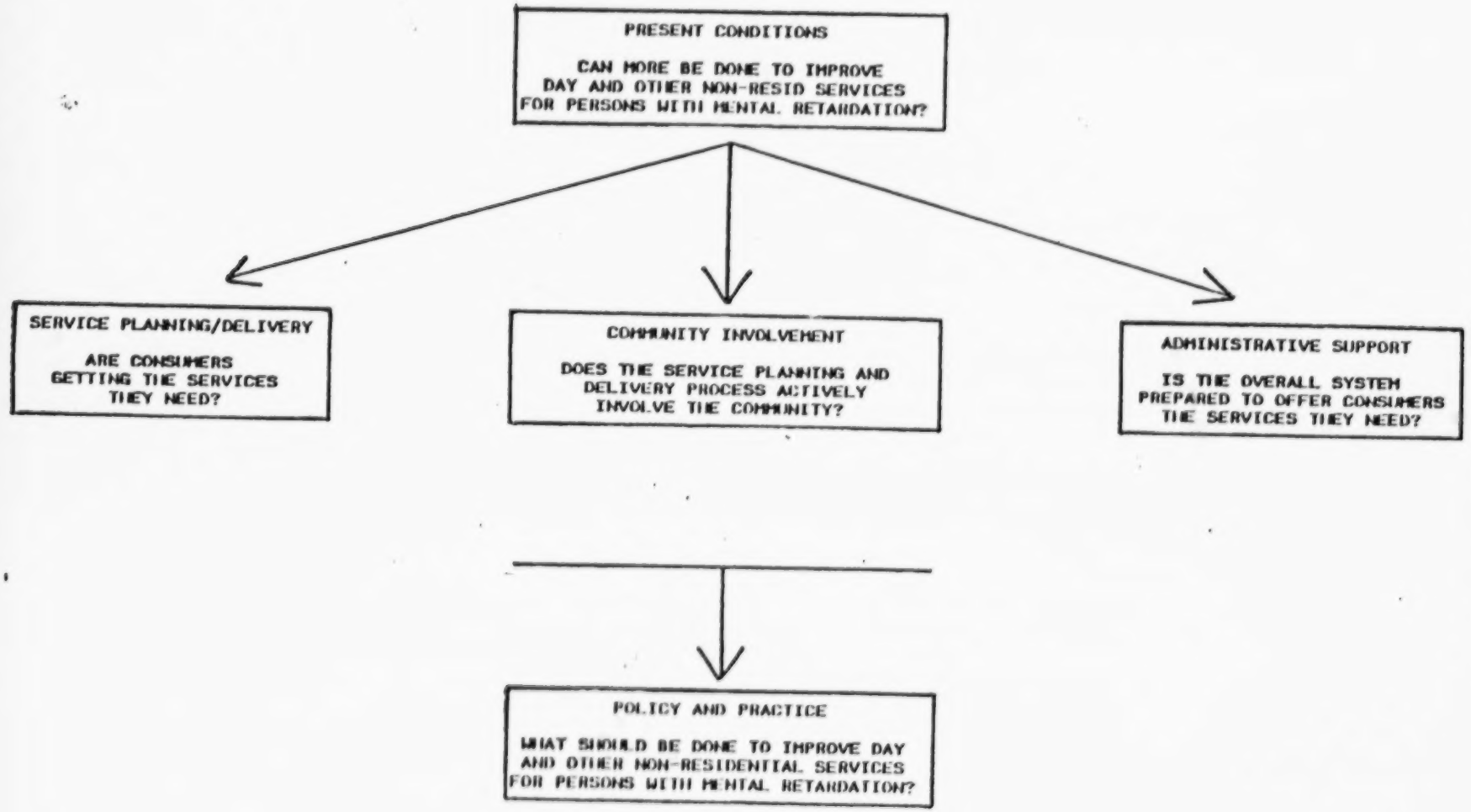

PRESENT CONDITIONS
CAN MORE BE DONE TO IMPROVE DAY AND OTHER NON-RESID SERVICES FOR PERSONS WITH MENTAL RETARDATION?
SERVICE PLANNING/DELIVERY
ARE CONSUMERS GETTING THE SERVICES THEY NEED?
COMMUNITY INVOLVEMENT
DOES THE SERVICE PLANNING AND DELIVERY PROCESS ACTIVELY INVOLVE THE COMMUNITY?
ADMINISTRATIVE SUPPORT
IS THE OVERALL SYSTEM PREPARED TO OFFER CONSUMERS THE SERVICES THEY NEED?
POLICY AND PRACTICE
WHAT SHOULD BE DONE TO IMPROVE DAY AND OTHER NON-RESIDENTIAL SERVICES FOR PERSONS WITH MENTAL RETARDATION?

Figure 24: Conceptual Framework

questions regarding the ISP process, a significant omission given that the THE key member of the team is the consumer;

* Program/Service Availabilty. The adequacy of programs in terms of their availability was checked across numerous service categories;

* Program/Service Accessibility. Making a program available to consumers is a necessary but not sufficient step to developing a superior service system. Additionally, available services must be made easily accessible to consumers; and

* Program/Service Content. Examining and judging the value of the specific content and service processes made available to individual consumers was beyond the scope of this project. However, general opinions regarding the quality of the program/service content was sought.

- Community Involvement. The importance of involving the local community in developing an effective system of services is well documented. In this light, the driving question within this component is:

  "Does the service planning and delivery process actively involve the community?"

  Four key aspects of community involvement were examined:

  * Involvement of Board Members. The involvement of boards of directors of community agencies and parent groups involved in state schools with various aspects of service planning and delivery was investigated;

  * Community Participation. The extent to which citizens of local communities are encouraged to participate in the service planning and delivery process was examined;

  * Use of Existing Community Resources. The extent to which existing community resources are used to complement public sector services was examined briefly; and

  * Involvement of Private Sector Business. Most notably this topic was investigated with regard to vocational opportunities.

- Administrative Support. In developing service systems the need for a sound administrative infrastructure to support needed programs is often overlooked in favor of an emphasis on establishing direct services. Yet adequate administrative support is an essential element to effective system design. Thus, the driving question within this component is:

  "Is the overall system prepared to offer consumers the services they need?"

Five key issues related to administrative support include:

* Administrative Practices. The balance of power within a system to affect change and implement needed programs is often the focus of lively discussion. Ideally, the power to establish needed programs is distributed among key actors within a system in ways that facilitate program development as needed. In this light, the locus of control within the present system was considered;

* Adequacy of Funding. Sufficient funding to carry out policy mandates is an absolute necessity. Opinions regarding the adequacy of the present funding of services were evaluated;

* Service Delivery Staff. The success of the mental retardation service system is dependent on its capacity to recruit, train and retain competent and caring staff. Opinions regarding the status of direct care staff were examined;

* Licensing and Quality Assurance. It is vital to assure that programs meet basic minimum standards (licensing) and that the system strives toward services of the highest caliber (monitoring and evaluation). The mechanisms used for program licensing and monitoring and those used to assure the quality of programs were examined and opinions regarding their adequacy were reviewed; and

* Flexibility. To respond to the individual needs of consumers and to implement changes in the state-of-the-art, programs must be designed to accommodate change as needed. Opinions regarding the present system's flexibility in this regard were examined.

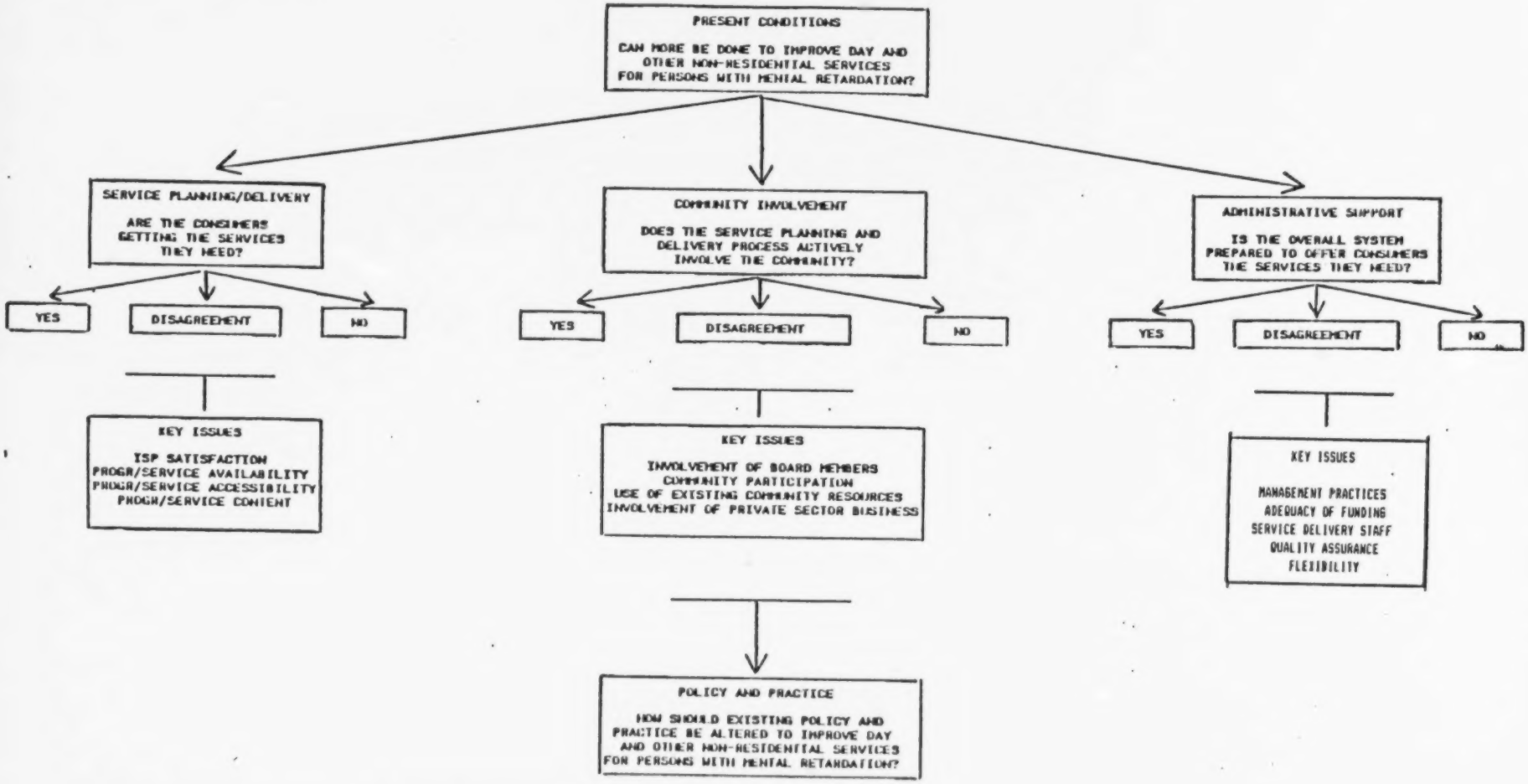
- Policy and Practice. The driving question of this component is:

> "How should existing policy and practice be altered to improve day and other non-residential services for persons with mental retardation?"

No issues specific to this question were generated. Instead findings pertaining to the issues noted within previously stated components of the conceptual framework are used to form a response to this question and these are presented as recommendations in Section V.

In subsequent subsections information pertaining to each of the first three components noted above are presented. Figure 25 displays these components with their driving lead questions and shows the

Figure 25: Conceptual Framework With Driving Questions and Accompanying Issues



major issues that are addressed under each. For each component and accompanying issue, the information collected is presented to show how those interviewed responded and to illustrate areas of agreement and disagreement.

B. Service Planning and Delivery

In addition to the quantitative results from the closed-ended questions presented in Section III, survey respondents provided a substantial amount of information in response to the open-ended questions contained in the survey. These qualitative results are presented in this section along with a brief interpretation of the results as they relate to each issue highlighted within the conceptual framework.

The driving question within this component is a basic one: "Are consumers getting the services they need?" The study dealt with only four of the numerous areas that could be considered when developing an answer to this essential question. Each of these four areas are addressed briefly below.

1. ISP Satisfaction

As the data from the quantitative results reflect, the responses provided by family members, administrative staff, and area MR coordinators indicate a fairly high degree of satisfaction with the ISP process. In addition, state school and regional center administrators were given an additional opportunity to provide open-ended comments on the ISP satisfaction questions. Note, however, that their number is small. So, while generalizations cannot be drawn from these responses, the issues identified by respondents are worth noting:

- It is difficult for professionals to consistently participate in the ISP meetings because of their responsiblities in day programs;
- For some of the older state school residents, parents are no longer available to attend and participate in the ISP process. Thus, there has been a gradual shift toward volunteer involvement; and
- While the ISP process is a very dynamic one, the character of the ISP document depends on the philosophy of the team. "A custodial team produces a custodial plan."

It is notable that these three issues relate to the persons participating in the ISP process rather than the content of the ISP document. At least among state school administrators, there appears to be an acknowledgement that the client ISP process cannot be separated from other issues such as the quality of professional staff.

2. Program/Service Availability

In addition to the quantitative questions regarding the availability of day and other non-residental services, throughout the survey respondents mentioned specific services or programs that they felt were important to develop or expand. While it is only reasonable that different parts of the state will need or desire different resources, many common needs were identified. Respondents associated with community-based programs specifically mentioned the following areas of program need:

- programs that work effectively with consumers who have multiple handicaps (deafness, blindness, dual diagnosis, physical disabilities);
- day services for aging consumers;
- programs specializing in computer technology and employment options within the growing service industries; and
- emergency/crisis residential services.

Many of the responses from family members, citizen board members, executive directors, and mental retardation coordinators went beyond traditional day programs and addressed the need for family support services and consumer social/recreation opportunities. Respondents from each one of the categories specifically mentioned the need for additional respite care programs to support families. With regard to social and recreational opportunities, family members identified the need for more integrated programs, and more activities for persons with severe handicaps. Program administrative staff indicated the need for more consumer advocates and ways of developing individual leisure time skills and hobbies.

Significantly, four out of six family members from state schools responded that social and recreational opportunities for consumers were generally inadequate. As in the case of the family members associated with community-based programs, most respondents appeared to be answering the question as it related to their own family member. It appears that family members associated with institutions as well as community-based programs see a need for increased social and recreational opportunities for persons with mental retardation.

3. Program/Service Accessibility

It is possible for a program to exist and yet not be accessible to all those consumers who seek it. For example, a community may have several types of respite care programs, but none may serve consumers exhibiting severe maladaptive behavior. Program accessibility problems identified in this study pertain to client characteristics, community acceptance, transportation, and the movement of consumers from more restrictive to less restrictive programs.

It is somewhat difficult to differentiate some of the respondent's comments with respect to program availability versus program accecssibility issues. While some respondents continue to advocate for entry into existing programs, others may seek the development of new programs to serve specific populations. In the present study, respondents identified the following populations as being in need of increased opportunities to receive services:

- persons with autism
- persons with dual diagnoses; and
- persons with severe handicaps.

Several community based respondents also commented on the availability of appropriate community services designed initially for those without disabilities, but they complained that consumer access is prevented because of negative social attitudes. Similarly, several respondents from different categories suggested that improvements could be made to help consumers participate in existing social and recreational activities.

Transportation problems can also prevent consumers from accessing programs and services. Family members were the only group asked specifically about transportation. Of the responding family members associated with community-based programs, just under half (12 of 28) described difficulties with day program transportation. Of the 12 family members reporting transportation problems, the issues related primarily to availability and reliability of the service, and inadequacies of the vehicle. Institutional programs are not immune to transportation difficulities. Three out of the six parents indicated that they knew of transportation problems. Two parents mentioned a lack of vehicles available for transportation to

recreation programs, while one parent complained about vehicle breakdowns and a lack of transportation alternatives.

Finally, consumers receiving services may not be able to access different programs as their abilities and needs change. One measure of this phenomenon was obtained by asking administrative staff whether or not adequate opportunities exist for clients to move on to new programs as they grow more skillful. The majority indicated that, given a dearth of alternative community programs, they have great concern about the availability of appropriate options. For example, one workshop director projected that if programs were available, 75% of his clients would be ready for on-site supported employment. Similarly, 10 of 11 mental retardation program coordinators noted that many persons receiving non-vocational day habilitation services could profit from a more vocationally oriented program.

Nine state school and regional center program directors responded to the same question regarding the adequacy of opportunities for consumers to move onto new programs. While three of the respondents indicated that programs are in place and consumer movement is possible, three others gave negative responses, and one pointed out that opportunity for movement to new programs is dependent on the level of the program needed. At least one issue emerging from the responses to this question is identical to a problem identified by community-based respondents. Movement within the system is limited and consumers get "stuck." Overall, the lack of alternative program options in many parts of the Commonwealth inhibits the consumer's ability to obtain services or to move among programs of varying restrictiveness as needed. This latter condition only makes matters

worse because clients movement up and out of the system is stymied, reducing the system's capability to accommodate new clients.

4. Program/Service Content

It has already been noted that this survey did not focus on the specific content of the programs offered to consumers. Comments in this area came primarily from family members and from consumers. Within the qualitative portions of the survey, family members from state schools and regional centers expressed concern over the amount of time spent on paperwork by professionals involved in the day programs. The time devoted to paperwork is viewed as limiting the time available for direct consumer contact as well as training and supervision of direct service staff. One parent sees his/her role in the day program as "keeping the staff on their toes."

Finally, it is important to note that consumers, when asked what they would do to improve their own programs, identified social as well as vocational items for improvement. Several consumers would like to get a job or have more contract work and more pay. Others focused on things they would like to learn such as typing and cooking. Significant numbers of consumers indicated a desire to go on more field trips.

C. Community Involvement

Programs and services for persons with mental retardation and their families cannot exist in isolation. Therefore, this component addresses the following question: "Does the service planning and delivery process actively involve the community?"

1. Involvment of Board Members

In Massachusetts, one of the ways in which citizen involvement is formalized is through the establishment of citizen boards for

community agencies, and through parent groups at state schools and regional centers. Area mental retardation coordinators expressed varying opinions regarding the involvement of citizens in the development of services for persons with mental retardation. While some respondents focused on the roles that citizens play on numerous planning committees, others stressed political and advocacy activitites. State school and regional center administrators provided differing perspectives when asked about the involvement of parent group members and other citizens in the activities of the facility. While one administrator sees the parent group as being strictly an advisory board, another respondent specified a number of projects and activities accomplished by the parent group. These activities included offering seminars and workshops, fundraising, and doing community outreach work.

2. Community Participation

Numerous respondents, predominantly family members and citizen board members, commented that there is a great need to improve community understanding and acceptance of persons with mental retardation. Board members recommended that additional resources be put into educating the public on the benefits of community day and residential services. One individual suggested the use of television and radio spots, and the establishment of a toll free phone line to obtain information and use as a referral service. Family members also identified increased community awareness and acceptance as a key ingredient to improving the quality of life for persons with mental retardation.

Responses given by state school and regional center administrators appear to reflect diverse philosophies on the

interaction of institutional facilities and the community. While some respondents indicate that interaction is minimal, others describe "enormous community outreach, contact and participation in the local community." One state school administrator focused on the "sociological isolation" of the institution and called for more volunteers and the creation of interaction mechanisms such as clubs, formal networks and senior citizen centers to "break down social barriers." From a different perspective, another state school administrator stressed the fact that institutions should be sharing their strengths and resources with the community.

3. Use of Existing Resources

As noted in the section on program accessibility, appropriate community services and programs for persons without disabilities may already exist, but consumer participation may be prevented because of negative social attitudes. Similarly, consumer participation may be limited by the fact that there are few programs set up to support consumer use of existing community responses.

4. Involvement of Private Sector Businesses

This issue was raised primarily with regard to vocational training and employment opportunities for persons with mental retardation. Of the seven state school administrators responding to the question concerning the identification of a main issue of concern, four respondents talked about developing stronger links with the community. Two of those responding specifically addressed the need for contacts with businesses. One administrator complained that his facility did not have the business contacts to facilitate competitive employment options for consumers. Another respondent suggested that there is a need to shift the focus from expanding sheltered workshops to expanding job sites.

D. Administrative Support

Although many of the issues discussed within this section were not addressed directly in the questionnaires, respondents signaled the importance of the issues by commenting on them in many of their qualitative responses. General issues concerning administrative support include the following need areas:

- increased accountability and monitoring;
- elimination of duplication;
- focus on quality rather than quantity;
- improved communication between the Department of Mental Health and vendor agencies; and
- improved communication and cooperation among state agencies (e.g., DMH, DPH and DPW regarding Medicaid funded programs).

Five more specific issues are addresed in the remainder of this section.

1. Management Practices

During the compilation and analysis of the respondent qualitative comments, it became apparent that many of the very diverse complaints or suggestions focused on a number of differnt management practices. These comments often seemed rooted in feelings of frustration on the part of vendor agency personnel with respect to their lack of input into DMH policy decisions.

Comments pertaining to this topic include the following:

- "I am concerned that we always have to wait for a crisis to stimulate action --when one of our consumers needs services and DMH says 'no';"
- "Sheltered workshops need a business attitude. DMH treats workshops as any social service agency. They don't recognize the business aspects;"
- "They have to decrease the response lag of rate setting after all forms are submitted;" and
- "We need stable funding sources...3 year contract period design with yearly license review."

Overall, providers appear to see their oganizations as being able to function more efficiently if they had more input into the operational areas now in the hands of state agencies.

2. Adequacy of Funding

Funding problems were mentioned repeatedly as a major concern in relation to many issues. Family members, citizen board members, executive directors, and mental retardation coordinators all volunteered their perspective on this issue. When asked how DMH or their executive agency could assist them in their roles as citizen board members, 12 out of 22 respondents commented on financial issues. Specifically, board members focused on needing better payment for programs to meet adequately the needs of consumers, more money to provide programs for unserved community consumers, and prompter payments.

Similar issues were mentioned by the 22 out of 46 program directors identifying focal issues for the MR Advisory Committee to address. Program directors keyed in on their needs in terms of the following funding issues related to programs and support services:

- assurance that funding, support, and autonomy will increase for innovative programs in the community;
- money for program resources and recreational programs; and
- more money for "funded slots," more space, and additional staff.

Funding issues were also a concern of family members in regard to the quality of life and the social/recreational opportunities available to consumers. In addition to increased funding for existing programs, families want to see money spent on program expansion and program development. This sentitment was echoed by at least one mental retardation coordinator who made the following comment:

> "We need program development resources. Not just money limiting us to adding another slot in existing programs...We're stuck in the status quo."

3. Service Delivery Staff

Family members, citizen board members, executive directors, and area mental retardation coordinators consistently highlighted as key concerns the ongoing difficulty with recruiting staff and the high rates of turnover. These comments focused mainly on the inadequacy of staff salaries. For example, when asked to identify key issues for the MR advisory committee to address, the majority of executive directors place staff pay at the top of their list of concerns. Without a chance to earn a competitive wage, many potential staff seek employment elsewhere, while existing staff often leave for higher paying positions or to pursue other careers. Family members are also aware of staffing problems particularly in regard to staff turnover. One parent made the following comment:

> "The main concern is that we cannot keep our dedicated staff due to funding. The staff have to have degrees and therefore go for higher pay...Dedicated staff can do great things..."

Many respondents linked staff salary problems to the viability of the community day program system. Again, in response to the question regarding a focal point warranting attention and change, one area mental retardation coordinator replied:

> "...to advocate for funding to recruit adequate staff to make the community based day program system viable in the future. Staff recruitment is a major problem. We need money to pay staff adequately."

Respondents from state schools and regional centers expressed

concern over several of the same staffing issues articulated by persons associated with community based programs. When asked to identify a main issue of concern, four out of 11 program directors focused on staff concerns. Two respondents called for additional numbers of staff. Other respondents were more specific and focused on the need for staff with adequate training:

> "My greatest concern is lack of adequate staff to serve our extremely agressive and self injurious consumers. These consumers require such intensive interventions that consumers with lesser abilities receive less attention."

Staff training definitively emerged as an area of concern in many different portions of the interviews completed at the state schools and regional centers. While most respondents acknowledged the need for staff training, many persons expressed concern over the lack of clear administrative support for training. They called for the expansion of internal training opportunities and the infusion of expertise from other sources.

4. Quality Assurance

Area mental retardation coordinators and program administrative staff were asked a series of questions pertaining to licensing and monitoring. There were no clear differences in the content of the responses obtained from these two categories of respondents. When asked to identify strengths in the current licensing procedures, many community-based respondents commented on the validity, thoroughness, and consistency of the process. They indicated that current licensing procedures facilitate program adherence to current regulations and assure that consumers rights are protected. Additionally, several respondents commented on the quality of the

licensing personnel. They stated that licensors assist in resolving problems and are very cooperative, knowledgeable, and dedicated.

Although consistency was identified as a strength, at least five program managers cited inconsistency as a weakness of the current licensing procedures. Their comments appeared to focus primarily on inconsistencies between licensors and served to highlight the frequent duplication in licensing procedures among various state agencies. Such duplication is reported to be time consuming and results in excessive, redundant paperwork. Additional weaknesses pertain to the regulations themselves, poor communication of these regulations, lack of technical assistance, and the lack of positive feedback in the process. Specific comments include the following:

- regulations are not written for community-based programs;
- system does not allow licensor to evaluate the quality and tone of interactions in the programs;
- need for more communication between licensing agencies; and
- need for technical assistance and funding to help programs correct their deficiencies

Suggestions for improving the current licensing procedures relate closely to the weaknesses identified. These suggestions include developing regulations for specific types of programs, eliminating licensure requirements for programs that are CARF approved (Commission on the Accredidation of Rehabilitation Facilities), adding a section on more qualitative elements, providing increased technical assistance to programs, and generally being more positive and consistent.

This issue is somewhat different for programs associated with state schools and regional centers due to the fact that institutional programs are reviewed by Deparment of Public Health (DPH) surveys,

rather than as a part of a licensing process. Generally, the respondents associated with institutional programs appeared to feel positive about the DPH survey process. It is viewed as a means of helping program staff assess its practices and assists in the identification of areas needing improvement. However, all four of the respondents identifying weaknesses in the DPH survey process pointed to an emphasis on record keeping rather than on direct observation. It was suggested that the survey teams should interview direct service staff and spend more time in the program areas.

In addition to licensing, the study addressed the adequacy of monitoring as a method of assuring program quality. Program administrative staff and area mental retardation coordinators were asked the same series of questions -- strengths, weaknesses and suggestions for improvement -- with regard to current program evaluation procedures. There did not appear to be any significant differences in the content of the responses from these two groups of respondents. Several people praised the involvement of well qualified parents and professionals familiar with consumer needs and services. The evaluation process was viewed by these respondents as being consumer centered, facilitating "self introspection and perspective leading to program improvement," and supportive of future program development. Yet the respondents identified a number of weaknesses in the current evaluation procedures. Cited most frequently as weaknesses were:

- a lack of standardization and consistency;
- the informality of the process; and
- duplication of effort.

Additionally, some program directors complained that they have been

unsuccessful in finding qualified individuals to participate in evaluations. Suggestions for improvement stressed the need for standardization and formalization, the development of goals and objectives to relate to specific program types, and streamlining of the evaluation process.

Responses from state school administrators and institutional program directors were very similar to the responses coming from persons associated with community-based programs. Duplication is a problem as is the lack of standardization and what is perceived to be excessive paperwork.

5. Flexibility

Persons responding to our survey indicated a strong desire for greater flexibility in program design and the use of financial resources. Increased flexibility was seen as a key ingredient in the ability of programs to respond rapidly to technological innovations, advances in habilitative practice, and changes in the economic climate. The concern is not simply to expand opportunities within existing models, but to have a system that will facilitate the development of more appropriate and innovative services and programs, such as supported employment and family support services.

Similarly, community-based program administrators expressed a strong desire for greater flexibility in their use of funds. The issue mentioned most frequently was the need for flexible funding for specialized equipment such as computers.

V. POLICY AND PRACTICE: RECOMMENDATIONS AND FUTURE INQUIRY

The primary goal of this project was to identify means for improving those services offered to persons with mental retardation in Massachusetts. In this light, to guide the review and interpretation of project findings, the following question was posed:

> "How should existing policy and practice be altered to improve day and other non-residential services for persons with mental retardation?"

Findings stemming from the 177 persons interviewed show that though much of the service system is working well and is much appreciated, numerous aspects of present policy and practice must be altered to increase the system's capability and effectiveness. Three areas warranting attention include:

- The Availability of Services. Services available are insufficient in both capacity and variety for meeting the current demand, leaving many consumers without needed services and others served inappropriately;
- Overall System Flexibility. There is a need for greater system flexibility in program design to make maximum use of individual consumer strengths, and to capitalize on advances in habilitative practice and economic opportunity; and
- Direct Care Program Staff. Attracting and maintaining qualified direct service staff remains a crucial concern, threatening to undermine the viability of programs, especially those in the community.

The 13 recommendations emerging from this project reflect a variety of concerns and ideas for improving the current system. Each is presented below under one of the three key areas noted above. These recommendations are not presented in any particular order or priority.

A. The Availability of Services

Survey findings show that a number of services are available within the Commonwealth, but that these are decidedly insufficient for meeting current demand. Services deemed to be particularly inadequate include family supports (e.g., respite, specialized home care), the range of day services, and social-recreational programs.

The lack of alternative program options in many parts of the Commonwealth inhibits the consumer's ability to obtain needed services. In some cases, services need to be reorganized within existing programs so that they better meet consumer needs. This type of reorganization makes it unnecessary for consumers to make frequent program changes as his/her needs evolve. Curently, when a program change is deemed appropriate, programs of varying restrictiveness may not be available. This latter condition is especially troublesome because consumer movement up and out of the system is stymied, reducing the system's capability to accommodate new consumers and contributing to the development of long waiting lists.

The absence of needed services must be addressed promptly. The benefits of services to support and enhance the efforts of families who provide home care to persons with mental retardation are growing increasingly apparent, prompting decision makers across the country to develop comprehensive family support services. Regarding day programs, the absence of vocational instruction and support for significant numbers of adults with mental retardation is unacceptable. Steps must be taken to see that these persons do not remain inactive, but are provided the opportunity and supports they need to enhance their vocational potential and begin contributing to the overall state economy. Moreover, the number of persons who will

soon graduate from Chapter 766 special education programs must be taken into account and appropriate services for these persons must also be planned. To help correct these conditions, the following eight recommendations are offered:

1. Consider the preferences of consumers regarding the direction of services

Too often those concerned with the welfare of persons with mental retardation take well meaning action on their behalf without considering satisfactorily the stated preferences and long term goals of the consumers themselves. The consumers interviewed in this project demonstrate unquestionably that --overall-- they are quite capable of responding to the questions posed to them. These findings are consistent with studies completed elsewhere showing that persons with mental retardation can provide accurate information regarding their life circumstances and service preferences, given competent interviewers and properly worded questions.

This is not to suggest that all persons with mental retardation be placed in sole charge of the services they receive. The MR Committee recognizes that many such persons have disabilities severe enough to limit their capacity to participate significantly in such decisions. Moreover, given that the most preferable decisions are those that are informed, consumers cannot be expected to make serious life decisions and influence systems planning without first becoming informed. In this regard, the long term role of knowledgeable persons working on behalf of consumers cannot be overlooked.

Beyond the consumer participation encouraged at Individual Service Plan meetings, we must and can do more to involve consumers in systems level planning, seeking their opinion regarding the

choices that must be made to improve services. The MR Committee urges that a study be made to examine systematically the current service preferences of consumers in Massachusetts and to find ways to incorporate their opinion into overall systems planning.

2. **Encourage the involvement of family members in the Individual Services Planning Process and as active members of community boards.**

Family members are often unaware of the ISP process and of their potential for influencing this crucial process. Family members who are educated about the activities of the ISP team prior to, during, and following periodic ISP meetings are able to function more effectively as advocates for their relative with disabilities than can family members whose involvement remains uninformed. Informed family members are more likely to take advantage of opportunities to shape the development and provision of the service plans generated for their relative with disabilities. To facilitate informed family involvement with the ISP process steps must be taken to provide family members with systematic instruction regarding the goals of the ISP, how the ISP team functions, the family's role as an informed advocate, and what can be done to appeal unpopular team decisions.

Additionally, family members must be encouraged to participate in planning services at the "systems" level. Toward that end, family members ought to be encouraged to serve on community vendor agency governing boards. Family members are capable of bringing to these boards a perspective not available to professionals or other concerned citizens, enhancing the board's capacity for offering exemplary services.

3. **Establish policy and accompanying incentives to encourage the development of vocational models that offer increased community integration to consumers and involve local business interests with service development.**

These models are needed to offer consumers a means for increasing their independence from sturctured facility-based approaches. In such programs staff support is offered to consumers who work within community-based private businesses (e.g., supported employment). Where facilities must be used, means for integrating the vocational environment by hiring persons without disabilities to work alongside persons with mental reatrdation must be explored.

4. Consider the need for and value of expanding the number of segregated vocational programs in light of contemporary practice and trends.

Certainly, appropriate vocational programs are required for all, including those with severe disabilities. These persons, however, are not necessarily served best within segregated settings, given recent contemporary practice that calls into question such traditional approaches.

Before efforts are made to develop additional segregated vocational programs, the merit of such programs must be considered carefully. Moreover, a study must be undertaken to assess the functioning levels and service needs of persons with mental retardation awaiting services and already receiving service. Given such information, decisions regarding the vocational models that are in greatest demand may be made.

5. Establish policy and accompanying incentives to encourage the development of a comprehensive family support program.

The majority of persons with mental retardation reside at home with family members, especially during early developmental stages. Yet these families are provided few, if any, services to support and enhance their efforts. Though the Commonwealth has recently demonstrated an increased commitment to supporting families, existing

programs are insufficient. Clear policy, based on a "family driven" model, is needed to guide the development of a comprehensive system for supporting families and plans must be set in motion to assure its development.

6. **Create policy and incentives to capitalize on existing community recreation and transportation programs, expanding such programs through DMH only after community resources have been utilized to the extent feasible.**

The need for consumers to have greater access to various activities and increased recreational opportunity was noted by many of those interviewed. The role of the public sector in providing these services, however, must be carefully considered. Though the need for these services is apparent, traditional approaches involving contracting with local vendors may not be appropriate. Finding ways to build on existing community transportation and social-recreational options --designed for citizens without disabilities-- may prove to be sufficient and a better investment for the long term. Such solutions offer consumers increased opportunity for integrating themselves into a normalized life rhythm and involves local communities with the delivery of services. Thus, before moving to expand existing transportation or recreational programs sponsored by the Department of Mental Health, the circumstances of those requiring such services should be assessed. Subsequently, plans to address their needs can be designed that make the most efficient use of existing community and DMH resources.

7. **Assess the value of present means for monitoring the quality of programs and set plans for improving the quality assurance review process as needed.**

Consumers are entitled to some assurance that the services they receive are of the highest quality feasible and that, if

dissatisfied, proper channels for voicing their complaints are available. Review of project findings reveals that a variety of mechanisms are used to examine the quality of services, with self-review used most frequently. Yet many respondents suggested that present licensing and program monitoring mechanisms are inadequate. The concern prompted by this finding grows even more salient in face of previous recommendations calling for an expansion of certain types of services. As programs increase in number, the pressures exerted on the present quality assurance system will also mount. To assure that the quality of the services offered is satisfactory, steps should now be taken to assess the effectiveness of existing means for monitoring program quality and a plan devised for maintaining an effective quality assurance program for the long term.

8. Re-examine policies that exclude certain persons with disabilities from services

Survey respondents repeatedly voiced their concern over persons with disabilities in need of service, but who are frequently left unserved. These persons include, but are not limited to, those with autism or with severe and multiple disabilities, and others living with aging parents or in nursing homes. Committee members understand that present policy may well exclude certain persons from appropriate services, based upon diagnostic classification or some other exclusionary factor. The unmet needs of these persons, however, are in plain view. To correct this condition, a reassessment of present policy pertaining to these traditionally excluded populations is urged.

B. Overall System Flexibility

Given the recent rapid changes in our state economy, due in part to the influx of industries based in high technology, we in the Commonwealth should be acutely aware of the quickened pace at which change can occur. Survey respondents indicated a strong desire for greater flexibility within the service system to prompt more rapid responses to technological innovations, advances in habilitative practice, and changes in the economic climate. The concern is not simply to expand opportunities within existing models, but to have a system that will facilitate the development of new and innovative services and programs, such as supported employment and family support services.

Existing limitations on program development are closely tied to a lack of flexibility within programs and to an absence of sufficient programs into which consumers can move as their needs evolve. These conditions inhibit individual efforts to become as independent of formal supports as possible.

Survey respondents were concerned about not seizing the opportunity to train consumers in employment areas that are emerging within the Massachusetts economy. Within the Commonwealth, a few innovative programs have emerged that take advantage of the growing range of emoloyment options for consumers. The success and experience of these relatively few programs must be shared with service providers across the state. Similarly, there were repeated requests for more competitive work opportunities at all levels and long term supportive employment programs. To help correct these conditions, the following two recommendations are offered:

9. **Examine existing state level and policy administrative practice to identify those systemic barriers to program innovation and initiate plans for their reform.**

As service systems evolve, certain policies and administrative practices are set in motion to influence service delivery. Designed initially to promote the emergence of efficient and effective service, existing practice may serve eventually to maintain an increasingly rigid status quo, stifling needed innovation and reform.

At present, traditional community-based and institutional approaches to services are drawing fire, while alternative practices, calling for increased community involvement and integration, are gaining in popularity. What existing policies, administrative codes and practices, or attitudinal biases prevent service professionals from implementing contemporary habilitative strategies? How may they be offset? Of particular concern are the effects of these factors on the formation of family support services and various integrated vocational models.

10. Establish policy and accompanying incentives to encourage program innovation and reform.

Given the need to expand service capabilities and to increase system flexibility, steps must be taken to invite desired innovation or reform. Key areas that call out for such attention include integrated vocational models, family support programs, recreational programs, and transportation services. Development of highly regarded, state-of-the-art programs in these areas should be given the highest priority. The MR Committee urges that exemplary programs that already exist in the Commonwealth be used to guide the development of desired services in other parts of the state.

C. Direct Care Program Staff.

The success of the mental retardation service system is dependent on its capability to provide quality care within the most appropriate

settings. In this regard, the recruitment, retention and development of competent staff is crucial. Decision makers at the state level, however, often overlook the importance of establishing effective staff recruitment and support mechanisms, focusing instead on enhancing direct service capabilities.

Assuring the availability of competent staff in the Commonwealth has reached crisis proportions. Family members, citizen board members, administrative staff, and mental retardation coordinators consistently highlighted as key concerns the ongoing difficulty with recruiting staff and the high rates of turnover. Among those community day programs surveyed, turnover rates ranged between 0% and 153% per year, averaging 60%. Though not as high, turnover rates at state schools also prompt concern, ranging from 0% to 125% and averaging 31%. These conditions will likely not improve in the near future, given contunued low unemployment rates in Massachusetts and staff salaries viewed as markedly inadequate by many. Though not examined directly, many respondents argued that these conditions inhibit efforts to provide consumers with the types and amounts of services they require. Moreover, the quality of those services that are offered is not what it could be.

To help correct these conditions, the following three recommendations are offered:

11. **Every effort must be made to improve the salaries and benefits for direct care staff, especially those working in community programs.**

Simply stated, the salaries and benefits offered to direct care staff are inadequate, especially in light of today's highly competitive labor market. Though the problem exists within state schools, this issue is of greatest concern among those concerned with

community programs. The chronic inadequacy of salaries for community direct services staff is on the minds of many. The majority of the administrative staff interviewed placed "staff pay" at the top of their list of concerns. Without the financial means to pay staff a competitive wage, many potential staff seek employment elsewhere, while existing staff often leave for higher paying positions or to pursue other careers.

At stake is the long term viability of community programs. To make programs equally accessible and to expand program options the system must be capable of attracting and retaining a competent and caring labor force. In this regard the low pay scales offered by private vendors is of great concern, leading some to question the Commonwealth's commitment to providing quality community-based services.

12. Examine the existing labor market to identify types of persons (i.e., "labor pools") that are available to work in human services programs.

Given a shortage of available labor, human services employers must be acutely aware of the types of persons that are willing and available to provide direct care. Without such knowledge, employers may waste time and precious resources recruiting within labor markets where potential staff are few and prone to brief job tenure. In contrast, precise information regarding available and yet untapped labor may help employers to recruit staff more effeciently. Moreover, given an understanding of the types of potential staff available, plans may be set for systematically restructuring service patterns and for implementing staff development practices designed specifically to accommodate the strengths and needs of new staff.

13. **Greater use must be made of our community colleges to train prospective direct care staff for work in the human services.**

Staff development is a primary concern of those involved with community and state school programs. The benefits reaped by consumers, programs and local communities due to having qualified direct care staff on hand are well documented. High rates of turnover among staff, however, upset plans to increase their competence and enhance the quality of care they offer. Moreover, staff development efforts seem endlessly focused on teaching "entry level" competencies. The expense to agencies is enormous. Little return on initial investments in staff are realized, given that newly trained staff often leave within the year, requiring re-newed investment in freshly recruited staff.

The resources available through our community colleges can help alleviate this problem. Other states (e.g., Iowa) have developed means for using their community colleges as "staff training centers" for already hired staff. This tactic reduces the costs associated with staff development, making use of existing resources, and encourages community involvement with programs. Community colleges have also been instrumental in offering students instruction in how to provide various types of direct care, granting two-year associate degrees. Once graduated these persons are ALREADY prepared to begin work, minimizing the need for expensive staff development efforts.

Of course, the number of persons willing to provide direct care and participate in training programs is related somewhat to the compensation made available for their work. As salaries within the human services field in Massachusetts are made more competitive, however, the existing community college system and the staff support

services it can offer must not be overlooked.

D. Conclusion

Present discussion in Massachusetts regarding the status of day and other non-residential programs, and how they can be improved is needed and most welcome. Such discussion often grows lively in the face of the complex decisions that must be made and the overriding concern that consumers receive the services they require. Yet the commitment among many to the development of a superior system of services is in plain view.

The above recommendations suggest that building such a system will require the cooperation of many, including consumers, family members, neighbors, government officials at all levels, and professionals working both in the public and private sector. At the core of their efforts must be a firm resolve to forge an effective partnership among all those concerned whose purpose is to offer services of the highest quality to consumers within the most appropriate settings. It is our hope that this report and the above recommendations will provide needed information and stimulate further discussion directed at achieving this worthwhile end.